FIGHTING FROM THE FRINGES: THE DECISION-MAKING PROCESS OF MOTHERS USING COMPLEMENTARY AND ALTERNATIVE MEDICINE IN AUTISM

by

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Abstract

In this study a theoretical model “Fighting from the Fringes” was developed to help elucidate the decision-making process of CAM selection by parents of children with autism. Represented in this conceptual model are the processes of searching for answers, looking for alternatives and making choices. The mothers’ disenfranchisement and marginalization from conventional healthcare, stigmatization from society and the stress and isolation experienced, all prove pivotal to the decision-making process of CAM use in autism. By examining the narratives of the mothers who participated in the study, and utilizing a grounded theory approach to analysis the data, this theoretical model emerged. This model allows for an understanding of the thought processes behind mothers’ decisions to use CAM for their children with autism, what also emerges is an understanding of how the use of CAM allows them to maintain their self-identify as “good mothers”. Recommendations of the study offer suggestions that address the much needed support and education to families face with caring for and making treatment decisions for their autistic child.
Preface

To ensure that ethical considerations were maintained, the study was subjected to an external review by the University of British Columbia Behavioural Research Ethics Board and approval for the study was obtained. The Certificate Number of the Ethics Certificate was H11-01333.
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Dedication

To Finn, my sweet boy who teaches me so much every day and to all mothers of children with autism who shoulder their burden with love and grace, you are extraordinary.
Chapter 1

1.1 Introduction

The use of complementary and alternative medicine (CAM) is common among people experiencing health concerns, particularly chronic conditions. The literature reports rates of CAM use in the general pediatric population to be as high as 40% (Kemper, Vohra, & Walls, 2008), with rates of use by children with chronic illness even higher at 50% to 70% (McCann & Newell, 2006). Research into the use of CAM in autism is relatively scarce, and evidence regarding the types of CAM therapies used and motivations underlying CAM use in this population is not extensive. Moreover, an integrative review of the literature reveals that the studies that have been conducted employed a variety of methodologies. This makes it difficult to do a direct comparison of the data presented; however, studies do suggest that parents of children with autism use CAM (Christon, Mackintosh, & Myers, 2010; Hanson et al., 2007; Harrington, Rosen, Garnecho, & Patrick, 2006; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Mackintosh, Myers, & Goin-Kochel, 2007; Wong, 2009; Wong & Smith, 2006). While there is a large discrepancy in reported rates of CAM use in children with autism (31.7% – 92%), it is clear that its use in this population is significant. The literature, however, does not address which therapies are selected by parents of children with autism and how decisions are made with regard to which therapies will be used, including the motivation behind the inclusion of CAM therapies as part of autistic children’s treatment plan.

It is important to note that the decision-making process associated with children’s health care is different than that for adults. Decisions made about children’s health care and, particularly for young children, are almost always made by parents/guardians rather than the
child. Therefore, research focused on treatment decision-making in adults may not be transferable or generalizable to pediatric populations. The decision-making processes for CAM also differ from those utilized in conventional care, mostly due to the fact that there is less scientific evidence of efficacy and safety for most CAM therapies. As a result, there is a lack of support and often outright resistance from conventional medicine to the use of CAM in treatment plans. In addition, and likely in part because of the lack of support from mainstream medicine, personal beliefs and values related to health and illness may play a larger role in deciding on whether and which CAM therapies will be used.

Further investigation is needed to examine the predictors of CAM use in children with autism and to understand parents’ decision-making processes regarding CAM. Several decision-making theories and frameworks that endeavor to explain why and how people choose CAM therapies already exist; however, any attempt to understand CAM use by parents of children with autism must also consider the belief systems and values that underlie parents’ choices and their expectations with regard to outcomes of those treatments. In light of this, an integrative review of these theories and an assessment of their ability and transferability to explain how and why parents choose CAM for their autistic children are needed.

1.2 Definition of Complementary and Alternative Medicine

The National Centre for Complementary and Alternative Medicine (NCCAM) defines complementary and alternative medicine as “a group of diverse medical and health care systems, practices, and products that are not generally considered to be part of conventional medicine” (NCCAM, 2010). These include whole medical systems, such as homeopathic and naturopathic medicine; mind-body therapies like prayer and meditation; natural health products that focus on vitamin, mineral, probiotic and herbal supplements; manipulative and body-based practices such
as massage and chiropractic work; and energy therapies such as reiki and therapeutic touch (NCCAM, 2010). Other therapies that may be considered to be CAM include movement therapies and traditional healers (NCCAM, 2010). Complementary medicine refers to use of one or more of these practices in conjunction with conventional medicine, whereas alternative medicine refers to the use of these therapies in place of conventional medicine (NCCAM, 2010).

1.3 Description of Autism

Autism is a pervasive neurobiological developmental disorder that is thought to have a genetic etiology. It is typically diagnosed in the first three years of childhood (Hebert & Koulouglioti, 2010; Veenstra-Vanderweele, Christian, & Cook, 2004). Autism is defined as a spectrum disorder that includes a range of pervasive developmental disorders (PDDs) that were once considered to be discrete conditions but are now commonly classified as being on the autism spectrum. In addition to Autistic Disorder (aka autism), these include Pervasive Developmental Disorders-Not Other Specified (PDD-NOS), Asperger's Syndrome, Childhood Disintegrative Disorder, and Rett's Syndrome (United States National Institute of Neurological Disorders and Stroke (NINDS), 2009).

There are three key diagnostic criterion used to determine whether a child has autism: substantial deficits in the areas of social skills; deficits in the area of communication; and abnormal patterns of behaviour. These abnormal behaviours may include restrictive and repetitive motor movements, an abnormal focus or intensity on a task or object demonstrated as an inflexible observance of routines and rituals, and/or an unrelenting preoccupation with a component of an object (American Psychiatric Association [DSM-IV-TR], 2000).
Children with autism are not all affected to the same degree, nor will they all demonstrate the same deficits; however, in general they will all exhibit some degree of poor interpersonal relationship building, impaired social language or social interaction, and inflexible and ritualistic behaviours. Although they may be amenable to interventions that may reduce the severity of the symptoms, these deficits are largely permanent. In some cases, autistic children may also exhibit other non-diagnostic symptoms, such as difficulty with sensory processing, diminished cognitive functioning, challenges with learning and attention, gastrointestinal symptoms, insomnia, aggression, hyperactivity, impulsivity, anxiety, and irritability (Akins, Angkustsiri, & Hansen, 2010; Bethea & Sikich, 2007; United States Center for Disease Control (USCDC), 2006, 2012). Because the underlying condition cannot be “cured,” it is usually the management and amelioration of these co-morbid symptoms that are the focus of both conventional and CAM treatments (Akins et al., 2010). However, given the idiosyncratic nature of the presentation of autism and its severity, not all children will require or respond to treatment in the same way (Hebert et al., 2010).

The most current figures on the pervasiveness of autism are those from the USCDC, (2012) which reflect the rates of Autism in 2008. The research results found the rates of autism and PDD-NOS to be reported as 18.4 per 1,000 (or 1 in 54) for boys and 4.0 per 1,000 (or 1 in 252) for girls, with a gender ratio of 4:1 that favours boys. A recent study from California concluded that, in fact, incidences of autism are on the rise (Hertz-Picciotto & Delwiche, 2009). Quantitative analysis showed a 7 to 8 fold increase in the cases of autism, a rise that could not be fully accounted for by earlier and better identification, inclusion of milder cases of Autism Spectrum Disorder (ASD) or changes in diagnostic criteria (Hertz-Picciotto et al., 2009). The
researchers suggested further quantification of extraneous variables was necessary to explain this increase in autism rates.

Research into the causes of autism is ongoing, with a focus on genetic heritability and environmental influence on gene expression being viewed as the most likely origins. Causality between socioeconomic status, parental education, and autism have not been substantiated (Karapurkar-Bhasin & Schendel, 2007; Larsson et al., 2005) and links between maternal age and autism have been inconclusive (Glasson et al., 2004; Croen, Grether & Selvin, 2002); however, there is a positive association with paternal age (Lauritsen, Pedersen, & Mortensen, 2005). Monozygotic and dizygotic twin and sibling studies indicate that genetic susceptibility to autism is a factor, but that environmental factors and epigenetic influences also likely play a role (Newschaffer et al., 2007). Research into the environmental influences on gene expression include prenatal exposure to alcohol, tobacco, illicit drugs, prescription medication, heavy metals, infection, immune and endocrine factors, and obstetrical complications. While any of these may yet be found to play a role, at this point, the research has proved inconclusive (Newschaffer et al., 2007). Researchers have also acknowledged that it is likely that autism is not limited to one etiology; there may be multiple causes with overlapping impairments, which may explain the spectral nature of autism symptoms (Newschaffer et al., 2007). Presently, research findings with regard to the pathophysiology of autism remain inconclusive and definitive answers regarding the cause of autism, and therefore potential causes, are still largely unknown (Bethea et al., 2007; Newschaffer et al., 2007; Veenstra-Vanderweele et al., 2004).

As of yet, there is no cure for autism. Most children with autism will demonstrate symptoms of the condition throughout their lives, and as a result, many will also experience issues with independent living, employment, relationships, and mental health, despite their level
of intellectual abilities (Howlin, Goode, Hutton, & Rutter, 2004; Myers, Johnson, & American Academy of Pediatrics Council on Children with Disabilities, 2007). To date, treatments for autism have focused principally on behavioural interventions that take advantage of the plasticity of the developing brain to reduce the effects of deficits and address behavioural issues (Bethea et al., 2007). Applied behavioural analysis (ABA) is presently the preferred treatment (Levy et al., 2003; Levy & Hyman, 2008; Wong, 2009) and, while it has proven to be successful in improving the social, behavioural and communication skills of many autistic children, assertions made by some proponents that it is a “cure” are largely unsubstantiated (Herbert, Sharp & Guadiano, 2002).

Drug therapy and the use of psychotropic medications and atypical neuroleptics in young autistic children have not proven effective beyond symptomatic control of some autistic behaviours and, because of long term side effects, have been recommended only for limited use (Canitano & Scandurra, 2010; Myers et al., 2007). Interventions that increase serotonergic neurotransmission in autistic children are being explored with promising results but are still in the animal research phase (Bethea et al., 2007).

Parents’ beliefs about the etiology and trajectory of their child’s autism vary widely but, typically, the symptoms of autism are noted by of parents between the first and second year of life, most often between 14-19 months (De Giacomo & Fombonne, 1997). Researchers have noted that parents describe two different mechanisms of onset of autism symptoms; either it is present from birth or it presents later following what appears to be period of typical development (Goin-Kochel & Myers, 2005; Goldberg, Thorsen, Osann & Spence, 2008). This second, or “regressive” form of autism, is frequently first identified by parents as the perceived loss of expressive language in toddlerhood (Werner & Dawson, 2005). The perception of parents about
when their child developed autism is important since it may affect how and what treatment methods they employ (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010; Goin-Kochel et al., 2005; Hebert et al., 2010). Goin-Kochel et al., (2005) found that parents whose children exhibited autistic symptoms from birth were more likely to associate genetic factors as the cause, while those parents who perceived their children to have a regressive form of autism were more likely to look to environmental causes. Hebert et al.’s (2010) study also found that parents’ beliefs about the causes of their children’s autism impacted health care decisions in the area of immunization, family planning, and maternal mental health.

Despite these interesting findings, these studies also highlight the limited research that has directly examined a correlation between parental beliefs and their decision-making processes when it comes to CAM (Goin-Kochel et al., 2005; Hebert, et al., 2010). Indeed, the decision to use CAM has been seen by some researchers as a symptom of flawed reasoning and loss of rationality rather than as an intelligent response to a need not being met by conventional medicine (Beyerstein, 2001; Krauss, Godfrey, Kirk and Eisenberg, 1998). These researchers implied that the use of CAM is symptomatic of magical thinking and a desperate search for miraculous cures by noting higher levels of CAM use amongst parents of children with illnesses and disabilities (Krauss et al., 1998; Prussing, Sobo, Walker & Kurtin, 2005). However, studies that have focused on developmental disabilities (other than autism) have shown that a movement towards self-determination in health care and a need to control medical decision-making may also account for an increased selection of CAM by parents of children with disabilities (Hyman & Levy, 2005).

For families, receiving the diagnosis of autism for their child is devastating. Inconclusive research with regard to causation, ambiguous information about treatment options and potential
outcomes, as well as limited access to treatment for many families, leaves many parents of children with autism struggling to make sense of their child’s disorder (Akins et al., 2010; Hebert et al., 2010; Hyman et al., 2005; Valentine, 2010). Parents are also expected to assume the responsibility for deciding on the direction and management of their child’s treatment, a responsibility they may not want or have the capacity to assume (Akins et al., 2010; Hebert et al., 2010; Hyman et al., 2005; Valentine, 2010). Although CAM therapies are usually unsupported by any scientific research, many CAM therapies are associated with claims that these therapies directly address or even cure many of the symptoms of autism, making them attractive to families searching for treatment help (Akins et al., 2010; Levy et al., 2003).

Appendix A outlines the most common CAM therapies used in autism treatment and their associated claims. Al Anbar and colleagues’ (2010) study used a modified version of the Revised Illness Perception Questionnaire (IPQ-RA) to demonstrate that parents who believed the cause of their child’s autism was environmental were more likely to use nutritional and detoxification treatment while parents who believed their child’s autism was caused by a genetic factor were less likely to use CAM. Sadly, CAM therapies are often ineffective, and may result in increased financial and emotional burdens for the family (Akins et al., 2010). Despite these issues, many families persist in the use of these treatment options, perhaps because they hope and believe that doing something is better than doing nothing at all (Akins et al., 2010; Hyman et al., 2005; Levy et al., 2003; Myers et al., 2007).

In addition to social, behavioural and communication challenges, children with autism may have other problems, such as sleep disorders and gastrointestinal difficulties, which are challenging for families to manage and are not addressed by conventional behavioural treatments. These problems, along with the need to make decisions about how to manage them,
may cause considerable caregiver burden and stress for the family (Valentine, 2010). The absence of conventional medical treatments and the increasing availability of information on the internet and in popular media – often supported by anecdotal reports -- regarding the efficacy of CAM therapies make vulnerable families susceptible and willing to believe the claims of a cure that often accompany these therapies, despite a lack of substantiated research (Heflin & Simpson, 1998; Mackintosh, Myers & Goin-Kochel, 2005). Moreover, because of the lack of adequate conventional treatment resources, families are often left to choose CAM treatments, particularly in situations where not making a CAM treatment choice may mean their child does not receive any treatment at all (Valentine, 2010).

There is much speculation about the factors leading parents to choose CAM, including: parental hope, high levels of parental stress, the severity of the child’s symptoms, expectancy of good outcomes from CAM, perceived safety of CAM, and the influence of media attention on the efficacy of CAM (research, that up until now, has been mostly atheoretical). Families experience a great deal of stress prior to and at the time of diagnosis and guilt when trying to cope with their autistic child’s needs (Blacher & McIntyre, 2006). As well, parents must face the challenge of raising a child in a society that does not value children or adults with disabilities and the burden imposed on their family by a negative social attitude towards disabilities, inadequate financial support, and social recognition of the burden of caring for a child with autism (McKeever and Miller, 2004; Green, 2007). Families must contend with their grief and challenges of raising a child with autism going unrecognized due to society’s lack of awareness about autism and the perception that their children’s lives are less valued by society, compounding their feelings of stigmatism, isolation, and marginalization (Rowse, 2007). Green (2007) found that mothers of children with disabilities tended to view the burdens of caring for
their child with autism in terms of socio-structural constraints and not emotional constraints. Mothers who experienced stigmatization of themselves and their autistic children by society felt increased stress and caregiver burden (Gray & Holden, 1992; Gray, 2001). Despite feeling stigmatized and isolated, Gray (2006) found that families with autistic children strived to be normal and tried to find ways to socialize, and that parents used fewer coping strategies over time. This can be viewed as positive but may also reflect psychological adaptation of parents to intense stress. Perhaps somewhat counter-intuitively, many parents also reported feeling that raising a child with a disability to be a gift. This may reflect a move away from a focus by the family on the negative aspects of autism to a more positive conceptualization that demonstrates successful coping (Altiere & von Kluge, 2009; Green, 2007).

Because stress and coping are integral parts of the decision-making process in families of children with autism, a modified stress and coping model may suggest a theoretical framework that explains their CAM decision-making. However, more research is necessary to test this speculation and to better understand the thought processes that influence parent’s treatment choices for their children with autism (Esch & Carr, 2004). In addition, a review of the theoretical frameworks that underlie decision-making and health care choices is needed to test and illuminate the decision-making processes employed by parents of autistic children with regard to their decisions to use CAM. Conversely, if no theoretical framework exists to inform these processes, then the need for further research and the development of a suitable theoretical framework to explain this phenomenon is required.
1.4 Decision Making Theories

1.4.1 Normative theory. Historically, decision-making theories have taken a normative approach. The most well-known of these normative theories is the subjective expected utility theory (SEU). SEU posits that the attractiveness of the outcome of a decision is multiplied by the chance of it occurring. It assumes both the rationality of the decision maker and that analytical decision-making processes lead to the best outcomes (Broadstock & Michie, 2000; Slovic, Fischhoff, & Lichtenstein, 1977; Tversky & Kahneman, 1986; Tversky & Kahneman, 1992). This theory further assumes that people have distinct, unchanging, and quantitative preferences and beliefs that they use to make choices (Hibbard, Slovic, & Jewett, 1997). What this traditional theory fails to consider is the real life behavior, values, and attributes of the decision maker as a factor in choice making. Instead, it imposes mathematical boundaries on preferences and choices, while neglecting the psychological processes that influence an individual (Broadstock et al., 2000; Slovic et al., 1977; Tversky et al., 1986; Tversky et al., 1992).

Recognition of the inadequacies of this theory has led to a move away from purely normative analytical theories of decision-making to analytical theories that incorporate normative and descriptive theories. This includes behavioral decision theory; prospective theory (a purely descriptive model); and most recently, naturalistic decision-making theory models, which are an off-shoot of bounded decision-making theory (Broadstock et al., 2000; Klein, 2008). These theories and their potential ability to contribute to the understanding of the processes by which parents choose CAM are described below.
1.4.2 Behavioral decision theory. Behavioral decision theory consists of two interrelated theories: normative theory, which deals with prescribed courses of action that align themselves with the beliefs and values of the decision maker; and descriptive decision theory, which deals with how the individual incorporates those beliefs and values into a decision (Slovic et al., 1977). This theory operates on the assumption that a rational decision maker will survey a fixed set of choices that have been analyzed for their consequences and that will allow them to pursue an optimal resolution (Broadstock et al., 2000; Slovic, Fischhoff, & Liechtenstein, 1987). Behavioral decision theory recognizes that a person’s beliefs and preferences are changeable and are influenced by framing and context; in fact, it recognizes that preferences and beliefs may not even exist prior to being created in the decision-making process (Slovic, et al., 1984). This is particularly the case when choices are new, complicated, and unfamiliar (Hibbard et al., 1997). The way information is provided may also be highly influential and affect the person’s values and beliefs, especially if the person is confused by the complexity of the choices, which further limits the ability of the person to make a sound, reliable decision. Information that is disparate to a person’s expectations or is framed in a negative way may produce a more analytic scrutiny of the data (Klein, 1989). When information is intangible, however, and factors that may elicit fear, hope, or regret are part of the decision-making process, analytical approaches may not be an appropriate way to evaluate how choices are generated and considered (Hibbard et al., 1997; Ubel & Loewenstein, 1997).

1.4.3 Prospective theory. An alternative to SEU and behavioral decision theory is prospective theory, which argues that variances from normal decisions/choices are too frequent and regular to be ignored and, therefore, other considerations to normative decision-making process must be explored (Tversky et al., 1986; Tversky et al., 1992). This theory has two
phases; the first phase consists of the decision maker analyzing the likelihoods and outcomes of a problem that has been presented, potentially rejecting choices that are surpassed by other alternatives and excluding possibilities having common characteristics (Tversky et al., 1986). This phase allows for contextual influences to impact the participant’s normal practices, routines, and beliefs. In the second phase, the prospects are evaluated and either by domination of one prospect over another or by a comparison of values, the prospect that has the highest benefit to the decision maker is chosen (Tversky et al., 1986; Tversky et al., 1992). This theory allows that the decision maker will be risk adverse for perceived losses but will be a risk taker for perceived gains; and that the decision maker will react more strongly to a loss than they will to a gain. Tversky et al., (1992) posit that risk-seeking is more likely when the decision maker is faced with the possibility of a small sure loss versus a larger but more probable loss. Prospective theory claims to not require rationality, and to be non-normative, descriptive, and constructed to include the preferences of the decision maker (Tversky et al., 1986). It still requires, however, the decision maker to use an analytical cognitive process in a controlled setting that may not be a true representation of how people make decisions in the real world (Broadstock et al., 2000; Klein, 2008).

1.4.4 Heuristic theories. The need to explain why people do not adhere to a rational, normative form of decision-making resulted in the development of heuristic and belief models. These models suggest that people faced with the task of predicting outcomes and the evolution of probabilities will resort to a less complex method of decision-making (Kahneman, Slovic & Tversky, 1982). While the use of heuristics was found to be a common and economical way of making decisions, its deviation from the normative model of decision-making resulted in individuals – rather than the model itself -- being blamed for mistakes (Kahneman, et al., 1982).
Prior to the development of normative and analytical theories to explain how decisions are made, feelings, intuition, and availability were accepted as the predominant way that people assessed risk and made decisions (Slovic et al., 1984). This automatic and subconscious way of responding to choices (i.e., responses that occur instinctively and quickly) can be characterized as heuristics. Many heuristic theories exist to explain how individuals solve problems. Some of the more common heuristic biases include the representativeness heuristic, the anchoring and adjusting heuristic, the affect heuristic, and the availability heuristic. In the representativeness heuristic, probabilities are judged by the extent to which one entity resembles or originates from another entity. Stereotyping is an example of this heuristic (Tversky et al., 1974). In the adjusting and anchoring heuristic, which affects how people use intuition to consider choices, a person begins with estimation (the anchor) and then uses additional data to adjust that initial reference point (Tversky et al., 1974). The affect heuristic maintains that a human being's feelings or intuitions influence their decision-making process (Slovic et al., 1984). In the availability heuristic, how quickly a similar experience can be identified is used by the individual to predict the likelihood of something happening or its occurrence in a population (Tversky et al., 1974).

While all heuristic theories may have the potential to explain how individuals make decisions, for the purpose of this study, the affect and availability heuristics are examined more closely for their applicability to the phenomenon of study (Hibbard et al., 1997; Slovic et al., 1984; Tversky et al., 1974).

**Affect heuristic.** Reliance on feelings is a fast, easy, and efficient way to deal with complicated and unfamiliar choices and apprehension about the unknown (Slovic et al., 1984). However, affective decision-making has been criticized as being suboptimal to analytical decision-making, citing individuals’ vulnerability to manipulation, personal biases, and over-
sensitivity to small changes in their personal environment while lacking the ability to react to large scale changes. Slovic (1987) found people to be often misinformed, undereducated in how to assess risk adequately, and lacking in understanding of how these shortcomings limit their ability to make sound decisions. When asked, people will say they want as much information as possible to make a decision, but normative decision-making research has established that people can only process a limited number of options (Tversky, Sattath, & Slovic, 1988). They theorize that it may be beyond our cognitive capabilities to take large amounts of data from a multitude of sources and use it to make a decision. In fact, they suggest that people may prefer having someone else tell them which choices to make. Conflicting information may further increase the difficulty of processing information and, when faced with this scenario, individuals tend to adopt heuristic devices (Tversky et al., 1988). This is despite the fact that these biases may ignore critical information and lead to decision errors (Hibbard et al., 1997). The affect heuristic, while informative, does not clearly demonstrate how people make decisions, as not all of their choices are made based on affective decision-making but instead employ a more complex and contextual process. Analytical and experiential decision-making are not unconnected. Slovic, et al., (1984) reason that analytical thinking is not possible without being informed by affective thinking - how we feel about a risk factor impacts how we think about that factor; however, this differs from person to person.

**Availability heuristic.** The availability heuristic is another judgment bias that influences decision-making. This heuristic uses personal experiences to make decisions; however, if a person’s experiences are misleading then they may misjudge their risk. The limitations of the availability heuristic to support decision-making include unstable values and preferences and, in the face of conflicting information, difficulty processing information (Hibbard et al., 1997).
When dealing with familiar circumstances, individuals’ preferences are likely to be fairly consistent; but when dealing with situations, consequences, or choices that are unfamiliar, individuals’ preferences tend to be disorganized and inconsistent (Hibbard et al., 1997). The tendency is that outcomes that are likely probable will be undervalued compared to values that are fully probable - things that might happen are not as valuable as things that will happen for sure. A way to avoid decision-making errors based on heuristic devices is for the decision maker to have an understanding of both personal and systematic biases in their information, which most people are unable to determine (Slovic et al., 1984). This means that cognitive limitations have an adverse effect on individuals’ ability to make choices, especially in the face of risk and uncertainty, making predictions, and determining probability.

1.4.5 Bounded decision-making theory. Another shift away from the traditional analytical decision-making model is bounded decision-making theory. It was first written about by Herbert Simon (1945, 1956) who argued against rational, logical, and probability theories and instead chose to use an ecological and psychological lens to view human decision-making (Gigerenzer & Goldstein, 1996). Simon supposed that human minds have limited cognitive abilities and cannot cope with extensive amounts of information -- a contrast to the enlightenment and inferential traditions of normative theory (Gigerenzer et al., 1996). He argued that following a utilitarian framework of thinking about all the possible choices and the outcomes associated with each choice, and then calculating their utility and alternatives to achieve optimal outcomes is not how the human mind works when it comes to decision-making. He postulated instead that humans form simplified models of the world in order to understand it better, with a goal to finding a satisfactory outcome as opposed to the optimal one sought in normative models (Gigerenzer et al., 1996; Slovic et al., 1987). This theory, along with the heuristic and biases
belief model, minimizes the cognitive capabilities of humans to reason and make complex
decisions (Broadstock et al., 2000; Gigerenzer et al., 1996; Klein, 2008) and there is little
evidence to support that any of these decision-making theories leads to better choices
(Broadstock et al., 2000).

All analytical decision-making models have been criticized for being acontextual and for
not recognizing that beliefs and values that are significant to the decision maker will influence
decision-making, as will ethics, cultural norms, the influence of significant others, and additional
personal and social factors that the decision maker may have difficulty verbalizing (Broadstock
et al., 2000; Slovic, 1987; Ubel & Loewenstein, 1997). People may seek information as a way of
trying to feel more in control of a situation, regardless of whether or not the information is useful
in the making of decisions (Nichol et al., 2011). Analytical decision-making models also fail to
account for the decision maker’s efforts to minimize risk with alternative choices and gain
control over the situation, processes that people making healthcare choices frequently engage in
(Broadstock et al., 2000).

1.4.6 Natural decision-making theory. The natural decision-making (NDM) model
grew out of bounded decision-making theory. It is a dynamic model wherein options and choices
are not viewed sequentially; similar to bounded theory, a satisfactory rather than an optimal
choice is the goal. This theory strives to explain how people make decisions in real life settings
and allows for both automatic and analytical processing that normative structural models do not
(Klein, 2008). Broadstock et al., (2000) suggested that individuals are able to explore choices
analytically even when information is inconsistent, contrary to the decision maker’s
expectations, negatively framed, or challenges their beliefs. These factors lead to deeper scrutiny
and reflect individual differences in processing and analytical ability (Broadstock et al., 2000;
Klein, 2008). NDM does not take the structured, linear approach of normative and semi-normative decision-making theories, which involve evaluating relationships between the choices given and the decisions that are made. Instead, it tries to understand the processes used to make the decision. It is interested not only in the options presented, but how they are produced, which elements are contemplated, and which risk factors are identified as significant. In this way, NDM strives to understand not only what decisions are made, but more importantly, how they are made (Broadstock et al., 2000). A limitation to the use of NDM in the field includes the possibility that choices presented in a controlled setting reflect what is important to the researcher and not to the decision maker; thus, the ability to capture the processes accurately outside this setting can be difficult (Broadstock et al., 2000; Lipshitz, Klein, Orasanu, & Salas, 2001). NDM also fails to account for the role of incidental or integral affect or emotion in the decision-making process; however, research shows that integral affect may in fact, play a crucial role in NDM (Mosier & Fischer, 2010). NDM development has also been limited to proficient decision makers; NDM relies on the experience of the decision maker, within the context of the decision-making situation, as a factor in how decisions are made (Broadstock et al., 2000; Klein, 2008; Lipshitz, et al., 2001). Because of this, information about how novices make decisions in areas and situations that are unfamiliar is unclear.

1.4.7 Shared decision-making theory. Shared decision-making theory (SDM) believes that people, who are experts about themselves, are able to make satisfactory decisions about their own health based on their values and beliefs in conjunction with a health care provider who is an expert in the biomedical field (Légaré et al., 2008; Towle & Godolphin, 1999). SDM is useful principally when clinical situations have several evidence-based options and when differences occur in the measurement of risk and benefit amongst various patients (Barry, 2002). SDM
ensures that patients are fully informed of both the benefits and risks of their choices based on best practice evidence, ascertains patients’ preferences related to choices, allows that their desired level of involvement in the decision-making process be considered, allows for the transfer of information between patient and healthcare provider and that the information is understood, and recognizes the uncertainty in the decision-making process (Elwyn, Edwards, & Kinnersley, 1999; Légaré et al., 2008). While ideal in concept, SDM is not currently being well utilized in the practice arena (Elwyn et al., 2003; Légaré et al., 2008; Makoul, Arntson, & Schofield, 1995). An integrative review of the SDM literature found that the concept is inadequately defined and there presently is no collective definition (Makoul, & Clayman, 2006). The authors concluded that a definition that incorporated the existing research and delineated the elements essential for patients and physicians to operationalize SDM is necessary (Makoul et al., 2006). Research also indicates that health care professionals may be selecting patients whose contexts and characteristics make them amenable to SDM and overestimating their desire to be involved (Kiesler & Auerbach, 2006). There has been a tendency in the application of SDM for the health care provider to supply the patient with information and then leave the treatment choice in the hands of the patient (Charles, Gafni, & Whelan, 1997; Kiesler et al., 2006; Pyke-Grimm et al., 1999). Studies have found that, while patients want information and treatment choice, they do not necessarily want to be solely responsible for enacting those choices (Charles, Gafni, & Whelan, 1997; Pyke-Grimm et al., 1999).

1.4.8 Healthcare utilization theories. Health care utilization models also provide a theoretical framework in which CAM and decision-making processes can be examined. Health care utilization models follow a systematic progression or pathway that utilizes stages to explain health-seeking behaviours or employs a determinants framework that examines the explanatory...
influences on the decision-making process. Andersen’s sociobehavioural model and the consumer decision-making model are two examples of healthcare utilization models - the primary determinant of these health care utilization frameworks being need or illness (Lorenc et al., 2009). Andersen’s sociobehavioral model has three factors that function in a sequential manner: predisposing factors such as demographics, values and beliefs; enabling factors such as availability and access to healthcare and the resources to pay for them; and evaluated and perceived needs (Andersen, 1968; Andersen, 1995). The sociobehavioural model’s strength lies in its ability to incorporate both objective and subjective elements from a variety of sources into the decision-making process (Andersen, 1968; Andersen, 1995). However, it does not account for the tremendous variability in the elements and procedures an individual may apply in the decision-making process (Sirois & Purc-Stephenson, 2008).

The consumer decision-making model allows researchers to describe a considerable amount of complex and varied influences on an individual’s decision-making process. The consumer decision-making model considers the role of rational, experiential, and emotional factors in decisions about health care (Kanuk & Schiffman, 2000; Sirois et al., 2008). The model consists of three conceptual elements that influence how people make decisions: external influences, which impact an individual’s behaviours and viewpoints, such as family, friends, society; the decision-making process, which considers motivation, personality, and need recognition (in this case, about a health issue); and post-decision behaviour, which includes evaluation of the choice (Kanuk et al., 2000; Sirois et al., 2008). The limitation of the consumer decision-making model is that it is not directly related to health and may not fully represent the diversity of factors that contribute to health care choices (Lorenc, Ilan-Clarke, Robinson, & Blair, 2009; Sirois et al., 2008).
**1.4.9 Health behaviour theories.** Health behaviour models, such as the Health Locus of Control model, Health Belief Model, the Theory of Planned Behavior and the Transtheoretical model, use a variety of concepts to explain the behaviors of individuals, with personal beliefs, attitudes, goals, and self-efficacy being the primary areas of focus. In health behavior models, these concepts are generally chosen over other influences, such as environment, cultural, and personality, which may not be as amenable to change. Health behavior models do allow for individual differences, as well as values, beliefs, and the willingness to carry out certain health practices, to be considered.

**The health belief model.** The Health Belief Model has traditionally been used for health screening and precautionary behavior (Becker, 1974; Redding et al., 2000). The Health Belief Model’s central tenets suppose that a person’s health behavior is based on their judgment of how vulnerable they are to an illness; how serious the outcome of that illness might be; whether modification of one’s behavior would avoid the illness; whether the benefit of behaviour modification is perceived to be higher than the risk and will require minimal cost, pain, or effort; and how effective the person believes a treatment will be (Becker, 1974; Redding et al., 2000; Rosenstock, 1974). It is these judgements that impact peoples’ decision to seek medical attention or adopt health-promoting behavior (Becker, 1974; Redding et al., 2000; Rosenstock, 1974). Identifiable variables such as education, age, and socioeconomic status mediate the likelihood of an individual adopting a health promoting behavior by indirectly influencing the perceived threat of an illness and the expected outcome (Redding et al., 2000).

**The health locus of control.** The Health Locus of Control model examines the extent to which people believe their health and the factors that affect it are under their control or in the control of others. The model is made up of two central concepts: internal beliefs that a person’s
health is affected by their behaviour; and external beliefs, which is made up of two aspects, chance and influential others (Wallston & Wallston, 1981; Wallston, 1992). In most research, the focus has been on the internal aspect, as the influence of others on a healthy person’s beliefs has not been found to be significantly correlated with outcomes and the belief that chance influences health has been reported to be more closely associated with a lack of control over one’s health (Wallston, 1992). A person’s health is contingent upon their behavior and, supported by the value of a positive outcome, they are motivated to act. However, just because a person values health and feels responsible for their health does not mean that they will feel capable of enacting the changes necessary. A person’s perceived control over their health is thus seen as being a more important concept in predicting health behaviours (Wallston et al., 1981). Bandura (1977, 1982) posited that concepts of personal control, such as competence and self-efficacy (i.e., the degree to which a person feels they can positively interact with their environment) have a more significant role in predicting health behavior than the locus of control.

**Theory of planned behaviour.** The Theory of Planned Behavior has two central tenets: that a person’s behavior is an expression of their choice and that people are rational beings. In essence, we behave in a particular way because we want to and how we choose to act is based on a rational decision-making process (Redding et al., 2000). The Theory of Planned Behavior relies heavily on the conviction that the intention to perform a behavior is a sound predictor that a behavior will transpire, with most of the research in this area concentrating on the likelihood of the behaviour and not the behaviour itself (Baranowski, 1992; Redding et al., 2000). The ability of researchers to establish a sound relationship between intention and behavior has been insubstantial, limiting the perceived utility of attitudes as a predictor of behavior (Ajzen & Fishbein, 1980).
Transtheoretical model. The transtheoretical model grew out of the other health belief models and differs in its perspective by seeing behavior change as a process that evolves, as opposed to a singular occurrence (Redding, et al., 2000). The transtheoretical model’s central tenet has a person moving through five stages in which cognitive or behavioral changes occur: precontemplation, in which change has not yet been considered; contemplation, in which change has been considered but not acted upon; preparation, in which a person has decided to change and is planning to take action; action, in which initial steps to behavior change commence; and maintenance, in which behavior change is sustained but the individual may experience relapses. These stages are not linear, and an individual may move back and forth between stages (Prochaska & DiClemente, 1983; Redding et al., 2000; Rosenstock, 1974). These stages allow for the examination of the variables that influence an individual’s progress and inform the development of effective interventions for problem behaviors (Redding et al., 2000).

Health behaviour models help inform our understanding of decision-making processes, influence the development of interventions, and provide further direction for research. These theories illuminate ideas and demonstrate how they are allied with one another or not; however, assessment of the different theories finds that their variations are based primarily on the focus of one concept over another and not a difference of outcomes (Redding, et al., 2000). The ability of health behavior models to inform contributory factors that influence health behaviors and their dependence on correlational designs to assess causal relationships has been called into question (Weinstein, 2007). While these correlational designs have been shown to be ineffectual and biased when used to determine health behaviors that are recurrent, such as medication adherence, or diet and exercise, they may be appropriate to predict health behaviors -- such as the use of CAM -- that are being encountered or experienced for the first time (Weinstein, 2007).
1.4.10 Theories of stress and coping. The transactional model of stress and coping, developed by Lazarus and Folkman (1984) is a framework utilized to assess how people cope with stress. The basic constructs of this theory include assessing what a person finds stressful, how they evaluate a stressor’s significance, what resources and options are available to deal with the stressor, and how they cope with the stressor. The transactional model of stress and coping considers environmental, personal, and situational factors and contexts, and the influence on how a person assesses a stressor, as well as their resources and coping methods (Lazarus et al., 1984). The value of the transactional model of stress and coping in health education, health promotion, and disease prevention, as well as its function as an explanatory framework of how people seek health care and support, has been well documented in the literature (Sloper, 2000; Taanila, Syrjaelae, Kokkonen, & Jaervelin, 2002). However, how this model is linked to decision-making has not been as well represented in the literature (Balneaves & Long, 1999; Bilodeau & Degner, 1996; Marshall & Long, 2010).

Janis and Mann (1977) proposed the conflict theory model that combines concepts of stress and coping with decision-making theory and identifies decision-making as a fundamentally stressful process, acknowledging the risk, uncertainty, and conflict inherent in decision-making. Conflict theory model is concerned with adaptive behaviours and cognitive processes that affect the decision-making process itself rather than the outcome of the decision (Janis et al., 1977). Unlike the transactional model of stress and coping, the conflict theory model fails to acknowledge the personal and social elements involved in decision-making and does not demonstrate that the use of these constructs leads to better choices (Balneaves et al., 1999; Marshall et al., 2010).
Balneaves et al., (1999) proposed an integration of decision-making and stress and coping theories to address the theoretical limitations of the conflict theory model and to position the concepts of stress, appraisal, and coping within the context of decisional conflict for women with breast cancer. They did this to address the lack of theory that acknowledged the stressful nature of decisional making and the dynamic nature of the constructs of the transactional model of stress and coping. They were able to reconceptualise these models by embedding the conflict theory model within the transactional model of stress and coping, thus allowing for the individualisation and subjective nature of the decision-making process, moving away from the condemnatory views supported by analytical models based on right or wrong choices (Balneaves et al., 1999). However, skepticism concerning the ability of researchers to measure and actualize the constructs of stress, appraisal, and coping remains; and attention to the influence of social forces on people’s decision-making processes needs to recognized (Balneaves et al., 1999).

1.5 Decision-Making Theories and CAM

In an effort to help health care providers have a better understanding of how peoples’ health care choices and the processes that accompany them are situated within a conceptual framework, many formal decision-making theories have been developed. While theoretical framework development has been substantial in conventional treatment decision-making, in the area of CAM the research has been primarily atheoretical (Sirois et al., 2008) and the applicability of existing theories to CAM decision-making is questionable (Caspi, Koithan & Criddle, 2004). A recent review of theoretical models used to explore the parental decision-making process of CAM selection for their children was performed by Lorenc et al., (2009). Of the 2,700 articles vetted for inclusion and the 22 articles that met the criteria for inclusion in this review, only one study focused on children. The lack of child-focused studies caused Lorenc et
al., (2009) to include articles on adult decision-making only. As a result of this limitation, the authors concluded that their review was unable to generalize findings about the use of CAM in children.

Lornec et al.’s (2009) systematic review also excluded models that did not take into consideration the values and beliefs of the decision maker, which -- as discussed previously -- are critical in understanding the processes and factors involved in the decision-making process. Instead, the authors choose to focus on models that tried to explain the psychosocial elements and ways in which the decisions to use CAM are made. Their systematic review revealed two dominant approaches: the health care utilization model and various health behaviour models (Lorenc et al., 2009). The health behavior models were capable of examining the individual differences, reasoning, beliefs, and values that are intrinsic to an individual’s decision to adopt or change a behavior and that intercede on the influence of external factors, when CAM was viewed as a health behavior (Conner & Norman, 1995; Lorenc et al., 2009). These internal factors had the benefit of being amenable to change. Turning to the specific models, the health locus of control model was able to predict CAM use in less than half of the studies, although it was able to demonstrate a relationship to CAM use and a person’s need to control their illness or treatment (Lorenc et al., 2009). In contrast, the transtheoretical model and the theory of planned behavior were not able to predict CAM use as individual theories; however, when combined, they pointed out the importance of personal beliefs, concerns, and external constructs, particularly the expectation of family members (Hirai et al., 2008; Lorenc, et al., 2009). A review of the research did not find the health belief model to have explanatory value in predicting CAM use. All of the health behavior models were perceived by Lorenc and colleagues (2009) to be limited
by the use of a singular point of view that restricts sources of outside influence from being integrated in the decision-making process (Lorenc et al., 2009).

Health behaviour models may not be complete in their ability to predict the decision-making processes involved in CAM use but they do demonstrate the fundamental beliefs that may influence them. CAM users desire a participatory role in their treatment decisions, have effective coping styles, and have a sense of self-efficacy about controlling their health. They also maintain the belief that the development of illness is affected by lifestyle and psychological factors (Bishop, Yardley, & Lewith, 2007). Research has demonstrated variation in pathways to CAM use and the user themselves; there are those who believe in CAM, those who are frustrated by conventional medicine, and those who are simply opportunists (Furnham & Kirkaldy, 1996; Furnham & Smith, 1988).

The predominant health care utilization model that has been used to explain the decision-making processes associated with CAM use is Andersen’s Sociobehavioural Model (SBM) (Lorenc et al., 2009). Lornec et al. (2009) found that, although the SBM model was able to include both subjective and objective variables from multiple areas, including social support that may encourage the utilization and perceived efficacy of CAM treatments, it was limited in its ability to name specific processes or health beliefs. The SBM is able to describe the sequencing of reasons that may contribute to the decision to use CAM, but is not able to fully explain the more convoluted and intricate non-linear processes that are often a part of decision-making (Sirois et al., 2008).

Heuristics may explain some of the factors that influence CAM use by parents. Despite there being little scientific evidence that CAM therapies are efficacious, parents perceive CAM as low risk, natural, holistic, and safe (Nichol, Thompson, & Shaw, 2011). Social influences,
such as information offered by friends and by other parents of autistic children who may make
claims that a particular CAM therapy is effective (Robinson et al., 2008), may lead parents to
view the therapy in a positive light and perceive it to be low risk. Additionally, conventional
health care practitioners’ inadequate knowledge about CAM and inability to educate parents with
information about risk mean that parents continue to perceive that these therapies carry limited
risk (Nichol et al., 2011). Heuristic theories, however, do not account for these cognitive
limitations and personal biases that have an impact on individuals’ ability to make well informed
choices, make predictions, and determine probability, particularly in the face of risk and
uncertainty.

The utility of SDM models for informing CAM use is limited; parents often see CAM as
being no different than the use of over-the-counter medication or non-traditional practitioner-
based treatments, but they may be reluctant to disclose their use of CAM to a physician for fear
of reprisal (Nichol et al., 2011; Wong et al., 2006). This occurs despite an expressed desire by
parents to participate in SDM with their health care practitioners, and speaks to an ongoing
dissonance between what patients say they want and what they do -- a dissonance that directly
affects health outcomes and the safety of care (Cockayne, Duguid, & Shenfield, 2005; Robinson
et al., 2008; Sibinga, Ottolini, Duggan, & Wison, 2004). Balneaves, Truant, Kelly, Verhoef, and
Davidson (2007) questioned the ability of women to make safe, informed choices about what
their personal treatment plans could include when conventional medicine failed to acknowledge
CAM. While many physicians are aware that their patients use CAM therapies, acknowledge
their obligation to discuss all relevant therapies with patients, and accept that some CAM
therapies may offer a benefit to their patients, most do not feel comfortable talking about CAM
due to a lack of training (Kemper & O’Connor, 2004). Physicians have also expressed concerns
about side effects, adverse reactions with conventional medications, and a delay in conventional
treatment as reasons for not engaging in conversations about CAM with their patients (Kemper et
al., 2004). CAM therapies remain at the margins of health care and these differing perspectives
between practitioners and patients mean that SDM is not an option at this time.

Using primarily mainstream CAM choices such as chiropractic therapy, massage
therapy, and provider-based CAM, Sirois et al. (2008) demonstrated that the consumer decision-
making theory may fit as a framework for CAM decision-making. However, they felt their
results may not be relevant for decisions made regarding self-administered CAM therapies.
Lornec et al. (2009) did not find that the consumer decision-making model to be appropriate to
explain CAM use in children; particularly, they noted that it lacked a health care focus and
neglected to integrate factors that were emotionally significant or would differentiate individuals
and their choices. The CDM model was found not to be preferred by parents who favoured a
shared or even passive decision-making role but did not desire the role of final authority or
singular decision maker (Pyke-Grimm et al., 1999).

Balneaves and colleagues (2007) developed the Bridging the Gap model to illustrate how
women with breast cancer made decisions about CAM in the context of conventional cancer
treatments. They demonstrated a gap in existing theories that failed to consider the conflict
experienced by this population when trying to align two seemingly paradoxical treatment
concepts. This conceptual framework aligned with theoretical perspectives that have assumed
that decision-making is an inherently stressful process and that a collaborative approach to
decision-making, between healthcare providers and patients, needs to be taken. Because there is
a paucity of research on how parents make decisions for their children’s health care, it is difficult
to assess if this model is suitable. While this model does address the conflict and stress
experienced when choosing CAM, the stress experienced by parents making choices for their children may be different.

1.6 Parental Decision-Making

Research about existing decision-making models and their ability to advance the understanding of the process of parental decision-making in autism treatment selection is limited; however, how parents make health care choices for their children with other developmental disabilities and pediatric cancers has been investigated in more depth. Examination of how existing decision-making theories are used in other areas of pediatric health to understand parental decision-making processes may provide a framework for the parental decision-making process for CAM and autism.

Studies that examined the role of SDM in parental decision-making for their children’s various health concerns found that parents and physicians had similar, positive views of SDM (Fiks, Hughes, Gafen, Guevara, & Barg, 2011; Merenstein, Diener-West, Krist, Pinneger, & Cooper, 2005). Conversely, however, their perspectives on how SDM was enacted varied significantly. Parents regarded SDM as an equal partnership with parents supplying the expertise about the child and the physician providing the expertise about the medical options. Physicians regarded SDM as a way to encourage families to accept the treatments recommended by the physician. This discordance of perspectives and understanding of how SDM is enacted lead to parents becoming mistrustful of the physicians, perceiving them as biased to one form of treatment over the other (Fiks et al., 2011).

Blank, Graves, Sepucha, and Llewellyn-Thomas (2006) found that the stress of diagnosis is often compounded with the stress of having to choose a treatment. Treatment choices may provide hope but also evoke anxiety, because of the pressure of making the right choice. Parents
may seek information as a way of trying to feel more in control of the situation, regardless of whether or not the information is useful in the making of decisions (Nichol et al., 2011). Pyke-Grimm, Degner, Small, and Mueller (1999) found this to be the case with parents making treatment decisions for their children with cancer; parents felt information regarding treatments, tests, and the possibility of a cure gave them a degree of control over the situation. However, parents also expressed a need for the information to be individualized, given based on the personalized requirements of the patient and their families, and offered over different stages of the diagnosis and treatment experience (Pyke-Grimm et al., 1999). Research has further demonstrated that patients who take an active decision-making role in their treatment want more abundant and diverse types of information (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Hack, Degner, & Dyck, 1994; Pyke-Grimm et al., 1999). However, when one turns this lens to parents, those who are expected to take an active role in decision-making even when they do not wish to do so, experience severe anxiety (Pyke-Grimm et al., 1999). When challenged by a serious illness, uncertain outcomes, competing choices, and time pressure, individuals can feel very vulnerable and encounter difficulty with decision-making, no matter how well informed (Charles et al., 1997; Ryan & Cole, 2009). Further research needs to be done to examine to what extent this personal responsibility may empower parents, or whether it increases their experience of isolation and societal marginalization (Prussing, Sobo, Walker, & Kurtin, 2005).

Bluebond-Langner, Belasco, Goldman, and Belasco (2007) found that, in parents of children with cancer, the search for treatment solutions became part of their identity as parents. Their child’s illness was the context that defined their role and responsibility as a decision-maker for their child’s wellbeing and the need to exhaust every resource to do so. They often chose
treatments even if the odds of these therapies working were unlikely, as their child’s life hung in the balance (Bluebond-Langner et al., 2007).

1.7 Decision-Making for CAM in Autism

Significant contextual differences challenge the utility of existing theoretical frameworks to explain the processes involved in CAM decision-making by parents of children with autism. When parents are given the diagnosis of autism, they are often left on their own by conventional health care practitioners to make complex -- and sometimes unorthodox -- treatment choices, with little or no medical guidance. This happens at a time when they are struggling to cope with the loss of their “ideal child” and are at their most vulnerable. Moreover, the notion that early intervention will improve outcomes, or even cure the child, adds further pressure. Parents must decide from among the array of treatments. These include conventional treatments for autism that are based in educational and behavioral intervention models, some of which are supported by scientific research; as well as less conventional treatments, which may include CAM, most of which have little to no scientific evidence. Factors such as availability, the intensity and cost of treatment, and what they believe might work best for their child, all influence their decisions. Further, the heterogeneity of autism makes the adoption of a “one size fits all treatment” plan impossible (Valentine, 2010). Parents are also asked to make decisions about treatments that may have limited availability or access in their geographical area, meaning that parents often have to wait or travel great distances to get the services they need or choose (Osborne & Reed, 2008; Valentine, 2010).

Osborne (2008) found that parents felt they were left with the enormous task of trying to find answers about treatments on their own through the internet, from other parents, and the literature. Valentine (2010) found that health professionals were reluctant to make specific
treatment recommendations as they might not fit with the family’s needs or abilities. At the same time, families wanted to have health professionals make treatment recommendations, as they felt unprepared to make the right choice. Similar to parents of children with cancer, parents of children with autism also make decisions for their children in the context of illness, but they are often unsupported by the health care system because of the lack of training for professionals and because of scarce and difficult-to-access resources and support. While autism is not life threatening in the same way as cancer is, it is a lifelong disability with devastating consequences for the child’s future, particularly if left untreated.

The diagnosis of autism forces parents to make choices about their children’s treatment whether they feel prepared to or not, and not making a choice is not perceived as an option (Valentine, 2010). In order to make choices about their children’s treatment, parents are obligated to take on one or all of the roles of advocate, educator, and consumer (Valentine, 2010). The role of parent as a rational, informed consumer who is able to make treatment decisions for their child, from a variety of options, imposes an assumption of expertise on parents that they may not have the desire or ability to enact (Jepson, Hewison, Thompson, & Weller, 2007; Valentine, 2010). Self-determination and patient-centered treatment models, however, may not help families to make sensible choices, but instead force them to make choices that are based in a consumer decision-making model that does not allow them the potential to opt out (Valentine, 2010).

The inability of health behavioural models to look beyond a singular point of view is particularly problematic when attempting to explain how CAM is chosen by parents of children with autism. Studies have shown that word-of-mouth and recommendations from friends have a profound influence on parents’ choice to use CAM, and that scientific validity is not the only
factor considered by parents (Green, 2007; Robinson et al., 2008). Green (2007) found that other parents and the Internet were the primary sources of information about treatments, with health professionals being the last choice as a source of information. Green (2007) found, however, that if the information was from a professional source, there was an unspoken assumption by parents that it must be scientifically valid.

The health locus of control model can be seen in the context of CAM decisions as a person’s attempt to control illness or treatment, which may be appropriate in parents trying to have some control over their child’s illness, particularly when they are disenchanted with lack of conventional treatment options and the sense of obligation to make a choice for their child. This model, however, may not be applicable to autism because it is unclear if they are empowered by the use of CAM. Most studies using health behaviour theories have considered practitioner-based CAM therapies that are not predominantly utilized by families (Robinson et al., 2008), including families of children with autism (Green, 2007; Harrington, et al., 2006; Levy et al., 2003; Wong et al., 2006; Wong, 2009). These models are also based on individual decision-making and not on the family locus of decision-making; therefore, these models may not be suitable for elucidating how CAM is chosen for children by their parents.

Marshall and Long’s (2010) study on how mothers cope with their child’s autism proposed moving beyond the Lazarus and Folkman’s (1984) post-positivistic model of stress and coping and instead recommended Snyder and Pulvers’ (2001) model, which allows for the study of the demands of having a child with autism along with the non-event stressors and circumstantial stressors that may accompany autism. They proposed that autism is not a stressor itself but rather is the center of a group of stressors that interact and amass over time and that may change the way mothers assign meaning to stressors as a way of coping (Marshall et al.,
The primary purpose of this study was to understand how mothers of children with autism cope with the stressors that accompany this situation and the behavioral and cognitive processes engaged. Mothers in this study spoke about learning everything they could about autism and its treatment and doing whatever they could to improve the symptoms of autism (Marshall et al., 2010). While the use of CAM was not explicit in this study, these findings lend themselves to a theoretical framework to further understand how mothers of children cope with autism, and how this might influence the context in which they make decisions, demonstrating the processes by which parents choose CAM.

1.8 Child Consent and Autonomy

It is important to note that the decision-making processes associated with children’s health care is different than that for adults because children are often excluded from the decision-making process, the choices for their health being made for them by their parents or guardians (Alderson, 2007; Coyne, 2006; Lorenc et al., 2009; Rowse, 2007). This is particularly true for children with disabilities, whose capacity to obtain and understand information and their ability to communicate their desires and consent may be especially limited (Rowse, 2007). Decision-making for children with a disability is often done with the best interest of the child in mind; however, these decisions may be based on the assumption that because they are disabled, they have a diminished quality of life and the choices offered by providers may reflect this (Campbell, 2002).

Two of the central principles of pediatric health care are family-centeredness and the inclusion of children in the decision-making process regarding their health. These are viewed as being fundamental to the ethical care of children. Despite this, the literature finds that children are rarely involved in the decision-making process (Coyne, 2006). Parents, children, ethicists,
and many health care professionals agree that children have a right to be informed, participate in
decision-making, and consent and assent to treatment (Alderson, 2007; Coyne, 2006; Martenson &
Fagerskiold, 2008). Arguments that children cannot understand or evaluate information and
risk, are unable to act in their own best interest, and lack the resolution to stand by a decision if it
goes wrong, are the same arguments historically used by a paternalist biomedical model to
prevent adults from making decisions regarding their health (Alderson, 2007). Although this
argument is intended to protect the child’s best interests, it also continues to protect adults’
authority over the decision-making process (Alderson, 2007). While children have the right to be
heard and participate in their care, like adults, the child should not be pressured to make complex
decisions regarding their care if they do not wish to do so (Coyne, 2006). Children’s involvement
in decision-making needs to be a process that considers the individual in collaboration with the
family and health care providers (McPherson & Thorne, 2000).

1.9 Conclusion

The decision-making processes for CAM differs from those utilized in conventional care
as they tend to reflect the personal beliefs and values of the individual while being more dynamic
and iterative (Balneaves, Weeks, & Seely, 2008). This means that the research focused on
treatment decision-making in adults and conventional medicine may not be transferable or
generalizable to pediatric populations or the use of CAM. This limitation forms the basis for
further research directed specifically at this group (Lorenc et al., 2009). In fact, Lorenc et al.
(2009) recommended that the use of CAM in children is an area that requires further
investigation. In particular, they suggested qualitative methodology be used to examine the
predictors of CAM use with children. Parents’ decision-making processes regarding CAM, what
belief systems and values underlie their choices, and their expectations related to outcomes of
those treatments all require further research (Hanson et al., 2007; Levy, et al., 2003; Lorenc et al., 2009). Research in the area of CAM use has been, up to now, primarily atheoretical (Sirois et al., 2008). Moreover, it is not just the lack of research done using theoretical models in the area of CAM use and children that limits the results, but the inappropriate fit of the theoretical models themselves to this area of study. In addition, in order to appropriately explore speculations that have been made about why parents choose CAM, more qualitative research is necessary to develop a framework that describes the complexity and contextual factors influencing the decision-making process and that explains the thought processes that influence parents’ treatment choices for their children with autism (Esch & Carr, 2004).

The intent of this study is to begin to do this work. It is intended that, from this study, a theory will begin to emerge that will allow a clear comprehension of why parents of children with autism choose CAM therapies. Snyder and Pulvers’ (2001) model of stress and coping that allows for nonevent stressors, or Balneaves at al.’s (2007) Bridging the Gap model, which aligned theoretical perspectives that decision-making is an inherently stressful process and that a collaborative approach to decision-making needs to be used, may provide frameworks for how parents of children with autism make decisions about CAM use. Conversely, it may be that a new theoretical framework is generated by the data; either way, it is the expectation of the researcher that this awareness will both further knowledge about the decision-making processes related to the use of CAM by families with autistic children and enhance health care providers’ understanding of this phenomenon. Ideally, it will also enhance the ability of health care providers to offer support and education to families faced with caring for and making treatment decisions for their autistic child.
Chapter 2 Research Design and Methodology

2.1 Introduction

A qualitative study design, using grounded theory methodology, was used to discover the complex process by which parents of children with autism decided to use CAM and the underlying motivations of these parents in their decisions to select therapies for their children with autism. Grounded theory is traditionally used to construct theory where none exists or to enhance understanding of processes when existing theories cannot explain the phenomenon, establishing it as an appropriate methodological approach for this study (Glaser, 1992; Strauss & Corbin, 1998). Research design, sampling procedures, and data collection techniques will be described. This will be followed by an in-depth explanation of the analysis of the data and the processes employed to maintain the rigor of the data. The chapter will conclude with the ethical considerations employed to maintain the confidentiality and comfort of the participants who generously shared their experiences for this study.

2.2 Methodology

This qualitative study used a grounded theory approach to explore, in-depth, the decision-making processes of parents who choose CAM therapies for their children with autism. The literature search did not determine a suitable theoretical framework to explain the processes of CAM selection by parents of children with autism; and so, in line with the basic tenets of grounded theory, a theoretical framework was analytically constructed from the data collected (Glaser, 1992; Strauss et al., 1998). Traditionally, implicit identification of a research problem is not encouraged in classic grounded theory; rather, the identification of the research problem and
the processes of resolution are identified through data collection and analysis and the emergence of the predominant experience (Glaser, 1992). A more modern approach to grounded theory methodology posits that researchers can legitimately draw from other sources, such as personal and professional experience or other research, for problem identification without compromising the research process or findings (Strauss et al., 1998). To this end, a Straussian approach was utilized to support the identification of a phenomenon, to legitimize the use of a literature search, and to formulate questions that satisfy the academic requirements of modern research. However a Glaserian or classic grounded theory approach was employed for the analysis of the data collected (Glaser & Holton, 2004). The utilization of a classic grounded theory approach to data analysis is highly structured and yet allows for a greater degree of flexibility through the use of constant comparison, which in turn supports the emergence of a conceptual theory rather than a forced thematic analysis (Glaser, 1992; Glaser et al., 2004). Glaser (1992) posited that everything is data – thus allowing data to be collected from a variety of sources, including personal knowledge -- and while true objectivity is not possible, the ability to maintain an analytical distance is integral to grounded theory, making reflexivity crucial (Glaser, 1992; Glaser et al., 2004). A Glaserian approach allowed the researcher to listen to and observe what was actually occurring and not separate out the data that fit a predetermined hypotheses; thus, the researcher was able to ascertain the primary phenomenon of concern to the participants being studied and how they resolved this issue, a strategy not endorsed with Straussian approach to data analysis (Glaser, 1992; Glaser et al., 2004; Strauss et al., 1998).
2.3 Sample Selection

2.3.1 Sample size and sampling. The number of participants needed in a study is related to the scope of the study, the ease with which the question can be answered, and the richness of the data collected (Morse, 2000). The methodology and design of the study also influences the required sample size; it has been predicted in the majority of qualitative research that no new findings will be noted by the researcher, or new experiences reported by the participants, once 18-20 participants have been interviewed (Morse, 1994). In this study, however, no limitations were set on subject numbers, as there was no way to predict the number of participant interviews required when utilizing grounded theory methodology (Glaser, 1992; LoBiondo-Wood & Haber, 2002; Polit & Beck, 2006). Fifteen mothers, along with two fathers as co-interviewees, were interviewed to fulfill the theoretical requirements of this study and ensure saturation of the data had been achieved.

The study sample was drawn from parents whose children participated in various autism programs in the Lower Mainland of British Columbia. Snowball sampling and recruitment of participants from independent websites was also used to obtain participants, as this is a population that can be difficult to access through clinical institutions and agencies. Purposive sampling was initially used to recruit subjects to the study. Participants selected included mothers and fathers. Every attempt was made to select participants with children of various ages and diversity in the severity of their autism, as well as number and types of CAM tried. Participants were selected across various socio-economic groups, ethnic groups, and province-wide locations to increase the heterogeneity of the sample (see Table 2.1).
Table 2.1

<table>
<thead>
<tr>
<th>Participant</th>
<th>Marital status</th>
<th># of children</th>
<th># child w/autism</th>
<th>Position of autistic child in family</th>
<th>Age of child with autism</th>
<th>Ethnicity</th>
<th>Education</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>3</td>
<td>2</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;, 3&lt;sup&gt;rd&lt;/sup&gt;</td>
<td>11, 12</td>
<td>Caucasian</td>
<td>College/trade school diploma</td>
<td>homemaker</td>
</tr>
<tr>
<td>2</td>
<td>married</td>
<td>2</td>
<td>2</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;, 2&lt;sup&gt;nd&lt;/sup&gt;</td>
<td>7, 9</td>
<td>Chinese</td>
<td>Graduate degree</td>
<td>Full time</td>
</tr>
<tr>
<td>3</td>
<td>single</td>
<td>1</td>
<td>1</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
<td>5</td>
<td>Caucasian</td>
<td>College/trade school diploma</td>
<td>Full time</td>
</tr>
<tr>
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<td>single</td>
<td>1</td>
<td>1</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
<td>6</td>
<td>Caucasian</td>
<td>High school diploma</td>
<td>Self-employed</td>
</tr>
<tr>
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<td>single</td>
<td>1</td>
<td>1</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
<td>12</td>
<td>Caucasian</td>
<td>Bachelor degree student</td>
<td></td>
</tr>
<tr>
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<td>2</td>
<td>1</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;</td>
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<td>Chinese</td>
<td>Graduate degree</td>
<td>homemaker</td>
</tr>
<tr>
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<td>2</td>
<td>1</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;</td>
<td>4</td>
<td>Caucasian</td>
<td>Some university homemaker</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>married</td>
<td>2</td>
<td>1</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
<td>5</td>
<td>Caucasian</td>
<td>Bachelor degree</td>
<td>Self-employed</td>
</tr>
<tr>
<td>9</td>
<td>married</td>
<td>1</td>
<td>1</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
<td>13</td>
<td>Caucasian</td>
<td>Graduate degree</td>
<td>Full time</td>
</tr>
<tr>
<td>10</td>
<td>married</td>
<td>3</td>
<td>2</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;, 3&lt;sup&gt;rd&lt;/sup&gt;</td>
<td>8, 6</td>
<td>Caucasian</td>
<td>High school diploma</td>
<td>Self-employed</td>
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<tr>
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<td>1</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
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<td>Latino</td>
<td>Some university</td>
<td>homemaker</td>
</tr>
<tr>
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<td>2</td>
<td>1</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
<td>5</td>
<td>Latino</td>
<td>Some university</td>
<td>homemaker</td>
</tr>
<tr>
<td>13</td>
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<td>2</td>
<td>1</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;</td>
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<td>Persian</td>
<td>Graduate degree</td>
<td>homemaker</td>
</tr>
<tr>
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<td>1</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;</td>
<td>4</td>
<td>Caucasian</td>
<td>Bachelor degree</td>
<td>homemaker</td>
</tr>
<tr>
<td>15</td>
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<td>1</td>
<td>1</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
<td>8</td>
<td>Caucasian</td>
<td>College/trade school diploma</td>
<td>Part-time</td>
</tr>
</tbody>
</table>
Once data collection and analysis began, a theoretical sampling approach was used to support the analytical process of constant comparison. The use of theoretical sampling meant that the researcher was able to analyze the data for emerging themes and concepts, explore these concepts for their theoretical significance by collecting further data from specifically chosen participants, and refine the theoretical constructs that emerged from the data collection and analysis (Glaser, 1992).

2.3.2 Eligibility criteria. The population considered in this study was comprised of parents, both mothers and fathers, of children with autism. Inclusion criteria for this study were as follows: (1) have a child between the ages of 2 and 16 years who had been clinically diagnosed with autism; (2) have used at least one CAM therapy (as defined in Appendix B) for their child; (3) live in the Province of British Columbia; and (4) speak and understand English.

2.3.3 Recruitment. Recruitment of research participants began once approval for the study was granted by the University of British Columbia Behavioural Research Ethics Board. Prior to this approval the researcher approached various autism service providers in the Lower Mainland (Appendix C) via email to assess their willingness to participate in the recruitment of study subjects. Once the University of British Columbia Behavioural Research Ethics Board had approved the study, the service providers that agreed to facilitate participant recruitment (ABA Learning Centre, ACT-Autism Community Training, and the Pivot Point Family Growth Center) were asked to forward a recruitment letter (Appendix D) from the researcher to their clients, post a recruitment poster in their office (Appendix E) and/or put a notification of the research study on their website. The autism service providers that agreed to facilitate participant recruitment through letters to eligible families used their databases to access these names. At no time did the researchers have access to these databases. Potential participants independently contacted the
researcher, either via the telephone or email, to express their interest in participating in the study and were then assessed for their eligibility to participate using the inclusion criteria.

Once the suitability of the participants was established, they were given a complete explanation as to the purpose of the study and what their participation would entail in a manner and at a level that they could understand. If they still desired to participate, they were directed to an on-line questionnaire (Appendix F) using Fluid Surveys™, a Canadian-based company that stores all encrypted data in Canada. This questionnaire included a cover letter that again gave a complete explanation as to the purpose of the study and let the participants know that by filling out the questionnaire they were consenting to participate in the study. A written consent (Appendix G) was also obtained by the student researcher in person prior to the commencement of the interview. The principle of autonomy was employed, meaning that all participants had the right to choose to participate, were free of coercion, could ask questions of the researcher, and could refuse to disclose information and terminate involvement in the study at any time (Polit et al., 2006). Twenty-three participants expressed interest in the study, 21 participants filled out the questionnaires, and 15 agreed to be interviewed, with the other participants withdrawing from the study of their own volition.
2.3.4 Settings. The interview data were collected in settings that were amenable to the participant and the researcher. A majority of the interviews were conducted in the participants’ homes or offices, two were done via the telephone for participants who lived outside the Lower Mainland, and two were conducted in coffee shops at the participants’ request. In five interviews, the participants’ autistic children were present in the home as well; however, at no time were the children interviewed or questioned. The children were present only to accommodate their parents’ desire to participate in the study despite lack of child care.

2.4 Collection of Data

Grounded theory methodology requires that the questions asked during data collection advance our theoretical understanding and that the research questions be refined as the data emerges. Several methods of data collection were employed, including questionnaires, interviews, and field notes. While specific questions were asked (Appendix H), these questions were modified during the data collection process through the use of data analysis to allow for the exploration of emerging themes. Participants were encouraged to share their stories and provide data that they felt was most significant to increasing the understanding about the process of CAM therapy selection for their children with autism.

2.4.1 CAM therapy use questionnaire. Initially, an on-line questionnaire (Appendix F) was sent to the participants to collect demographic data and information about the types of CAM therapies (Appendix B) selected by parents for their children. The questionnaire was not designed to generate quantitative data; the small sample size, purposive sampling, and nominal data did not permit any comparison or contrasting of this information. Instead, the data obtained from the questionnaire were analyzed by the researcher prior to meeting the participants to help direct the questions used in the personal interviews.
2.4.2 Interviews. Semi-structured, in-depth interviews, performed in a setting comfortable and convenient to each participant, were used to collect in-depth data from the study subjects. The interviews took place one time and lasted from 40-90 minutes, depending on the verbosity of the participant and the amount of information they needed to contribute to understanding the phenomenon. Interviews were digitally recorded and transcribed verbatim. Subjects were asked a series of open-ended questions (Appendix H) designed to encourage them to talk about the values, beliefs and processes that lead to their selection of CAM therapies for their child. For example, parents were asked about their experience of their child being diagnosed, which turned out to be a significant contributing factor to their selection of CAM for their child. The initial questions asked of the participants were broad but relevant to the phenomenon being studied and were refined as a result of the emerging data analysis (Glaser, 1992).

2.4.3 Field notes. Field notes were composed during and following the interviews to describe observational data not captured by the recorded data and personal narratives. Unlike memoing, field notes are a specific source of data that remain intact and are not classified or amended (Montgomery & Bailey, 2007). Key words, key phrases, and the researcher’s overall impressions of the emerging data were captured in the field notes.

2.5 Data Analysis Strategies

Integral to the development of theory in grounded theory methodology is the use of coding to conceptualize data (Glaser, 1992; Glaser et al., 2004; Strauss et al., 1998). The utilization of coding allowed the researcher to conceptualize the core patterns that emerged, moving the researcher away from the concrete and towards the abstraction necessary for theory development and allowing connections between seemingly disparate incidences to emerge.
(Glaser, 1992; Glaser et al., 2004; Strauss et al., 1998). For the purpose of this study, the data from all sources were analyzed as they were generated and were then compared against the findings from other participants using constant comparative analysis to determine if any particular themes, concepts, or commonalities emerged regarding the CAM decision-making process.

Two main analytical processes are employed in traditional grounded theory: substantive and theoretical coding. Substantive codes are used initially to conceptualize the experiential information in the data collected. In contrast, theoretical codes envisage the inter-relatability of substantive codes to one another, generating hypotheses that contribute to theory formation by allowing a fresh perspective of the data to be developed (Glaser et al., 2004). These two levels of analysis do not occur as discrete or linear processes. While the processes for substantive coding happen more when the researcher is first discovering codes within the data and theoretical coding happens later with the integration of memos and during the constant comparative process, they may also occur simultaneously (Glaser, 1978).

2.5.1 Open coding. The first step used to analyze the data in traditional grounded theory is the line-by-line or open coding of the transcribed interviews and field notes by the researcher. At this level, the researcher is trying to generate as many codes as possible by breaking the data down and trying out codes that may fit (Glaser, 1978). In these first steps of analysis, the audio recordings were listened to several times and the transcripts reviewed countless times to identify general codes and ideas significant to the phenomenon of study. This line-by-line coding forced the researcher to substantiate and saturate each category to achieve a theoretical construct that is truly grounded in the data (Glaser, 1978).
Once this line-by-line coding process was completed, the data and initial codes were further refined into substantive codes using the data management software program NVivo. These processes were not linear, but instead required the researcher to double back and verify repeatedly the fit of the data and relevance of the codes until no new information was yielded (Glaser 1978). The researcher became immersed in the data, allowing the use of two types of substantive coding; in vivo and social constructs. In vivo coding resulted from the language and wording used by the participants to describe their experience with autism and CAM therapies, and social constructs resulted from the researcher’s recognition of familiar concepts both personally and professionally; both were utilized in the open coding portion of the analysis (Glaser, 1992).

2.5.2 Substantive coding. Once the substantive codes were identified, they were compared to one another within and between the data groupings or nodes in NVivo to look for similarities and differences until the core concepts began to emerge. Some of these substantive codes included information-seeking behaviours; loss of trust; isolation; seeking partnerships; and the experience of living with autism. The emergence of core concepts in the interviews provided the researcher with a basis for further theoretical sampling and more selective coding (Glaser, 1978).

Selective coding started only when the core concepts and other secondary concepts were identified; the coding was limited to only those variables that may contribute to the development of a hypothesis (Glaser, 1992). This process of selective coding allowed saturation of the core categories, and the emergence of potential core concepts, which are explored further in the following chapter. While many potential core concepts evolved, the researcher focused on the analysis of one core variable and relegated the other core categories to a less significant position.
These processes were not linear but simultaneous throughout the data analysis. Theoretical sampling continued throughout these stages, informing which participants to interview, what questions to ask and allowing further data collection to take place to gain more insight into these issues and to establish saturation of the core categories (Glaser, 1992).

2.5.3 Theoretical coding. Theoretical coding is the last step in the data analysis and the researcher uses these codes to conceptualize how the substantive codes relate to one another. These codes represent social and social–psychological constructs that can be used in any arrangement to generate theory from the substantive codes. This final step revealed the core construct of “fighting from the fringe.”

2.5.4 Memoing. Throughout all levels of coding, memoing was used. Memoing is essential to grounded theory as it allows the researcher to develop ideas about the data and realize potential connections between categories, particularly during the phase of selective coding (Glaser et al., 2004). Memoing leads to the abstraction of the data and the formulations of hypotheses that are necessary for theory development (Glaser et al., 2004). It is crucial at this level for the researcher to ensure that the indications for constructing the theory come from the data and not from existing literature or researcher experience (Glaser, 1978; Glaser, 1992).

2.5.5 Diagramming. Once the initial coding was completed, diagrams were made for each transcript to have a visual conceptualization of the data and what was happening between the evolving concepts. These diagrams changed and evolved as themes and concepts emerged from the analytic process and movement was made towards a theory.
2.6 Rigour/Trustworthiness of Findings

Researchers of qualitative studies need to ensure that the data presented in their findings, and the assertions made, are credible (Polit & et al., 2006; Speziale & Carpenter, 2003). For this study, several steps were taken to ensure rigor and trustworthiness not only of the data but also of the evaluations and inferences drawn from that data. Data integrity was maintained by keeping an audit trail. Included in this audit trail were field notes, interview transcripts, coded data, memos, theoretical and process notes, and final drafts (Polit et al., 2006; Speziale et al., 2003).

In contrast to the concepts of reliability and validity used in quantitative research to imply rigour, Lincoln & Guba (1985) recommended three criteria for ensuring the trustworthiness of data: credibility, confirmability, and transferability.

**Creditability.** Credibility was addressed by prolonged engagement with the study participants and data integrity was maintained through the utilization of a peer review panel that consisted of Dr. Lynda Balneaves, Associate Professor in Nursing; Elizabeth Saewyc, Professor in Nursing; and Pat Mirenda, Professor in Educational and Counseling Psychology and Special Education. This peer review panel reviewed the data during peer debriefing, provided guidance during the analytic process and provided suggestions for improvements.

**Confirmability.** Confirmability was addressed through the auditing of data, bracketing, and the keeping of a reflexive journal by the author. The data in this study were collected by a single researcher who has a child with autism and has tried CAM therapies for her child. As a result, the researcher has a personal bias that may have interfered with the data being collected. To ensure that the data collected were unbiased and free of the personal beliefs and opinions of the researcher, bracketing was employed through the maintenance of a reflective journal. Although bracketing is more common to phenomenology, Glaser (1992) believed that reflexivity
was critical; therefore, bracketing is appropriate in grounded theory research as well. Failure to utilize this bracketing method could have caused the researcher to inappropriately lead the study subjects via the questions asked in a direction that validated her own experiences and beliefs (Polit et al., 2006; Speziale et al., 2003).

Transferability. Transferability of the data is not a goal of grounded theory, as it seeks to understand a phenomenon particular to a certain group; however, the use of thick descriptive data may make the findings generalizable to other populations experiencing the same phenomenon (Glaser et al., 2004).

2.7 Ethics and Human Subject Issues

Any research study involving human subjects requires stringent ethical considerations. Speziale et al., (2003) proposed the use of an ethics checklist to address ethical issues that require a critical consideration in any qualitative research project. The checklist was employed in this study to ensure that every care was taken to address potential ethical issues. The topics in the checklist, the guiding objectives to consider when employing it and the steps taken to meet these objectives are as follows:

a. Phenomenon of interest. The objectives to be met in this view include the research study’s relevance, importance, ability to benefit the participants and/or society, the researcher’s intentions are clear, and the use of a qualitative design (Speziale et al., 2003). The proposed research study is relevant and important to further the knowledge of CAM use amongst children with autism for both providers and families. It is the intention of the researcher to publish the results to contribute to the greater understanding of treatment options and issues within the population being studied.
b. **Review of the literature.** The objectives to be met in this aspect include a comprehensive literature review in which the basis for inclusion of articles is obvious (Speziale et al., 2003). To the best knowledge of the researcher, all available literature on the topic of CAM therapy use by parents of children with autism and related studies has been reviewed.

c. **Research design.** The objectives to be met in this section include the protection of the participants from physical or psychological harm, documentation of informed consent obtained without duress, and review board approval (Speziale et al., 2003).

Ethical dilemmas may have been encountered in conducting this qualitative research, including the generation of psychological discomfort in participants as a result of questions asked that may have elicited unresolved grief or distressing feelings surrounding their child’s condition. As a result, a list of support services available, at little or no cost to participants, was offered to all participants in case they encountered difficulty (Appendix I). Many times throughout the interviews parents expressed distress and desperation related to their child’s autism but at no point in the study did any of the participants express a need for the services available from the list provided.

Parents may have also disclosed privileged information regarding the treatment of their child that could be considered abusive and require legal action on behalf of the researcher (Polit et al., 2006; Speziale et al., 2003). The British Columbia Handbook for action on Child Abuse and Neglect (2007) defines neglect as:

> A failure to provide for a child’s basic needs. It involves an act of omission by the parent or guardian, resulting in (or likely to result in) harm to the child. Neglect may include failure to provide food, shelter, basic health care, supervision or protection from risks, to the extent that the child’s physical health, development or safety is, or is likely to be, harmed.
According to the Child Welfare Act of 1984, if anyone has a reason to believe a child is, or is in danger of, being abused physically or sexually or needs protection, they must report it to a child protection worker (Ministry of Children and Family Development (MCFD), 2008). This legal requirement to report any suspected abuse overrides any researcher-participant confidentiality obligation (MCFD, 2008). In the interest of full disclosure of risk to the participant, the legal need of the researcher to report any admission of abuse was contained in the consent form (Appendix H). All care was taken to avoid, prevent, and minimize the discomfort of the participants. To further ensure that ethical considerations were maintained, the study was subjected to an external review by the University of British Columbia Behavioural Research Ethics Board and approval for the study was obtained.

d. **Sampling.** The objectives to be met in this aspect are concerned with the protection of the participants confidentiality and evidence that no coercion of the participants taken place (Speziale et al., 2003). Confidentiality in interview-based qualitative studies is difficult; a lack of anonymity and the revelation of what may be intensely personal information means that steps must be taken to ensure there is no breach of confidentiality. The confidentiality of the participants in this study was protected by ensuring that the data were maintained in a secure location accessible only to the researchers. The collection and analysis of the data, done by only the author and the other primary and co-investigators (Lynda Balneaves, Elizabeth Saewyc and Pat Mirenda), ensured confidentiality of the participants was maintained. Identification numbers were used in place of names and personal or identifying information was deleted from the data and withheld in reports (Polit et al., 2006; Speziale et al., 2003). When the results of the
study are published, the author will make certain that the confidentiality of the research participants is maintained by ensuring that any identifying comments are excluded from the document, and that any recognizable characteristics of the subjects are changed.

The qualitative data collected via digitally recorded interviews were transcribed verbatim by a certified transcription service immediately following the interview and all personal and identifying information was withheld from the transcriptionist. The data analysis software, NVivo, was used to classify, sort, and manage the text-based data collected. Printed copies of consent forms, online questionnaires, memos, reflective journals, and transcribed and coded data were kept in a locked file cabinet accessible only to the researcher. All electronic data, including emails, consent forms, online questionnaires, and coded and analyzed data were kept on one password protected computer accessible only to the researcher. To further ensure confidentiality of all electronic data, password protected files, accessible only to the researcher and the supervisory committee, were created for all the electronic research data. Text and audio data will be stored in Dr. Balneaves’ private office at UBC for 5 years. After this time, the text data will be shredded and the digital audio recordings will be deleted.

It was hoped that, by doing this study, a theory would emerge that would allow a clear comprehension of how and why parents of children with autism choose CAM therapies. It is the expectation of the researcher that this awareness will enhance health care providers’ ability to offer support and education to families faced with the devastating diagnosis of autism and the responsibility of making treatment decisions for their children. The strengths of this study rest on the methodology; this is a relatively unexplored area of research and a qualitative grounded
theory study may prove to be foundational for other studies regarding CAM use and autism in populations unrepresented in this study.
Chapter 3 Findings

The core construct that emerged in this study was “Fighting from the Fringes.” The “Fighting from the Fringes” concept describes the decision-making processes of the mothers interviewed in this study. The theme captures the ways in which the mothers in this study coped with the diagnostic experience, sought information, selected CAM therapies, and evaluated their choices. The mothers in this study found themselves on the fringes of conventional health care as a consequence of the lack of acknowledgement of the mothers’ needs, the invalidation of their beliefs, and their concerns about their children not being addressed. The mothers also found themselves on the fringes of society a consequence of their children’s diagnoses, which isolated them and their child from society as a whole. These issues, along with limited treatment options within conventional health care and the need for mothers to search for alternative therapies, are also captured in the core construct, fighting from the fringe. Within this construct, the context of stress and isolation as a consequence of autism and the diagnostic process is also captured. To help clearly illustrate the complex decision-making processes involved in this theory, a diagrammatic representation is included (see Diagram 1).
The fighting from the fringe concept demonstrates three key processes mothers utilized in their CAM decision-making: searching for answers, looking for alternatives, and making a choice. This chapter will explain these processes using excerpts from the participants’ interviews to illustrate their decision-making, however, before examining the processes, an understanding of the context of stress and isolation and its impact on the mothers’ decision-making is necessary.

### 3.1 Living with Autism - an Awareness of the Context

In the context of the decision-making process, two major concepts were recurrent in the mothers’ stories of what it was like to live with autism: stress and isolation. An attempt to examine these concepts separately has been undertaken; however, because these concepts are so closely interdependent it is difficult to discuss them individually without some intersection.
3.1.1 The stress of autism. The mothers who participated in this study were open and forthright about the difficulties of parenting a child with autism. It was obvious that they were somewhat reluctant to appear to speak about their child in a negative way. Their children’s behaviours and the feelings that they experienced because of them, however, were so deeply woven into the fabric of their lives that they could not share their experience of choosing CAM without revealing the challenges of what it was like to live with a child who has autism. All of the mothers wanted the “outside world” to understand what they went through, what it was like to live their lives and why they made the choices they did.

For these mothers, much of the stress of living with an autistic child came from the behaviours that accompanied autism. Some of the words mothers used to describe these behaviors were: “unpredictable,” “difficult,” “a terror,” “full-blown meltdown,” “awful,” “relentless to stop,” and “out of control.” More than a few mothers spoke about the explosive and occasionally violent physical behaviours their child inflicted on them on a daily basis, such as “biting,” “hitting,” and “kicking.” More devastating to a small number of the mothers were the self-injurious behaviours that some children inflicted on themselves and the distress and concerns for their children’s well-being it invoked: “He used to bang his head. Like literally drop and smash his head. A cement sidewalk, it doesn't matter, like to the point where he'd have bruises and I was so worried about any kind of permanent brain damage.” (ID #15)

Many of the children also demonstrated ridged, obsessive, and inflexible behaviours, which the mothers described as “difficult” and “crazy.” One mother described the challenges of getting her 4-year-old autistic child to eat and the rituals necessary to do so: “He would not eat anything until he had lined it all up in a perfect [line]… Like he lined up everything!” (ID #14) Other mothers explained their children’s hypersensitivity to various stimuli such as being
touched, vacuum cleaners, blenders, Wi-Fi, and hyposensitivity to other stimuli such as pain and loud noises to be problematic. One mother described her son’s reaction to the vacuum cleaner in the following manner: “Oh, and then the real kind of [issue] was the noise thing, so plugging in the vacuum, his reaction [was something] I had never seen before. Sudden, crazy, and his reaction would just be so startling, and it was unsettling.” (ID #7) Another mother explained her son’s hypersensitivity to touch: “He couldn't be touched; he couldn't be hugged at school. I mean he was a friggin' mess.” (ID #10)

Managing and predicting the behaviours associated with hypersensitivity, such as temper tantrums, screaming, crying, and aggression was stressful enough for the mothers, but this was compounded by their concern for their child’s safety. Their children’s hyposensitivity to certain stimuli and inability to interact with, or negotiate in, the world around them without constant supervision necessitated the mothers to be continuously vigilant to danger. The mothers found themselves constantly assessing the potential environmental risks for physical injury to their children (e.g. things that might cause pain or danger) and monitoring their child’s impulsivity 24 hours a day. Several of the interviews took place in the homes of the families, and the precautions that they took to protect their children (e.g., door locks, gates, plug cover, fridge locks) were evident. Many of these precautions are often associated with toddlers and younger children, but were still in place in the homes of older children, demonstrating a need for safety and caution by these mothers that was interminable.

For those mothers whose children were nonverbal, their child’s inability to communicate was a major stressor. The mothers found it difficult to understand their child’s needs and frustrations and believed that the child’s inability to express themselves led to many of the behaviours they witnessed. One mother explained it as follows:
When he was young, he hit all the time, and it just seemed to me that he was upset. It wasn't that he was angry, although it came out as anger, but obviously something was bothering him and he couldn't [tell me]. (ID #4)

The unpredictability of their child’s behaviours, what would “set them off” and how to “get them back” were also hugely stressful for most of the mothers. Trying to get through day-to-day tasks, such as shopping, school and meals often proved to be incredibly challenging for families. One mother, whose 4-year-old son was present during the interview and very well behaved, explained it in the following manner:

But, that kind of stuff that people don't get is like, "You know what? I'm doing the best I can." And he is like this now [sitting quietly on the sofa] but he also has really bad days still where if anything goes sideways in the morning and I can't get him back, it's just like a snowball. (ID #14)

The children’s behaviours were not the only stressors; many of the children manifested a litany of symptoms of physical illnesses that the mothers believed accompanied autism and even contributed to their behaviours. Some of these health issues included unexplained rashes, eczema, chronic diarrhea, incontinence, GI pain, bloating, projectile vomiting, and nocturia in children who were toilet trained during the day. Several mothers reported observing “hard distended stomachs” accompanied by “arching, scrunching and screaming in pain.” The stress these behaviours manifested made many of the mothers feel occasionally overwhelmed, and the sense of powerlessness to prevent or predict these behaviours left some mother’s feeling helpless. One mother described living with the stress as “a terrible time in our lives” and another mother spoke candidly about her child’s behavior as “driving me crazy.” One mother of an 8-year-old child who had been diagnosed with mild/moderate autism 6 years ago described what it was like for her to watch her son have a “full blown meltdown” for hours at a time: “…behaviourally, I mean, you were… it was just like… some days I would just literally sit in a corner and cry.” (ID #15)
Some of the mothers with more than one child expressed concern about how autism had affected their “normal” children and reflected on the impact that living with an autistic sibling had on them. They did feel that the needs of their autistic children superseded the needs of their “normal” children and that they experienced guilt about them being left out, but noted that their autistic child needed more of their time. Trying to find a balance between their children was a source of stress as for them as well. One mother of two boys spoke about the impact of her younger son’s autism on her relationship with her older son:

My 5-year-old, he will take his father over me any chance he can get, or my mom, because they took him for the last year. I wasn't there for anything he did. So there's a price. And I don't treat them the same, and I know it. I'm working on that right now. (ID #14)

The stressors that affected the mothers in this study varied with the severity of their children’s autism, the number of children affected, the importance that they placed on the behaviour itself and other stressors in their life not related to autism. However, all the mothers agreed that they experienced a high degree of stress parenting a child with autism.

3.1.2 The isolation of autism. The second major concept that was recurrent in the context of living with autism was isolation. All of the mothers that participated in this study spoke honestly about the loneliness of parenting a child with autism. They used words like “alone,” “lost,” “nobody knows,” and “on my own.” They spoke about how other people did not understand what living with autism was really like, that many people “just have no clue what you deal with.” This lack of understanding from others made them reluctant to discuss their child’s autism or even disclose it. One mother of a young boy with autism discussed how the perception of people about what autism is or is not and their lack of insight and education on the part of others caused her to withdraw:

And you don't share that kind of things with other people because you don't how people… sometimes people are not firm about what is autism, what is it exactly. They
think, "Oh, your son has brain problems. Is he crazy? Is he going to a nurse?" or whatever, I don't know, a place that is going to be only for crazy people. And then they say "Oh, don't play with him because he is different." So we didn't share that much with other people. (ID #12)

These mothers reported feeling isolated not only from the general public but also from friends, family, and spouses. One mother talked openly about the impact autism has had on her friendships and the losses she endured because of it: “And I've lost a ton of friends. Not because I chose this route, but just because when you have a child that has this [autism]……” (ID #14)

All the mothers found themselves feeling isolated not only by the stigma of having a child with a disability but also by trying to fit themselves and their child into a world that does not accommodate the sensory and behavioural issues that often accompany autism. The difficulty of managing the unpredictability of their child’s behaviour in public when trying to accomplish day-to-day tasks and the reactions of people to this behaviour left them feeling angry, embarrassed, and misunderstood. The hostility one mother encountered in public engendered these feelings: “You're in the grocery store and he's acting weird, and it's like I want to turn to someone and be like, "Oh really? Get out of my face, really” (ID #14). Another mother described the reality of what it is like to arrange to leave the house with her son: “I have to plan much more and expect something may go wrong, have some backup programs; it make[s] their life more complicated” (ID #6). One woman who was a single mother spoke about the difficulty of managing her child’s behaviour and managing the social expectations of the public on how a child, who appears normal, should behave:

If you go somewhere and there’s a big line-up and there’s no way you can wait there and you have to go to the front and people are like ‘why are you going to the front?’ and it is not visually obvious to them so those kinds of situations or the unpredictability too. You don’t know from one day to the next what’s going to happen, you can’t come up with strategies, it might be one day its ok, the next day it’s not. I find it very...it’s isolating. Where we can go? Friends of mine, they go to children’s festivals and we don’t go. Unless I have somebody, I pay for somebody
to come with me, but then it’s probably too much anyway so we don’t go. Or we don’t visit anybody.” (ID # 3)

This isolation and exclusion from social settings because of erratic and often difficult to manage behaviours affected not only the parent’s sense of isolation but also isolated the child. One mother spoke about her adolescent son’s experience in society: “Other kids like to try to avoid him” (ID # 6). While another mother spoke about her grade eight son’s experience: “He was bullied right from kindergarten right up through. We changed schools to get away from that and it didn't work, and just it's been a continual thing” (ID # 9).

The mothers also shared their heartbreak of being isolated from their child. They found their autistic child to be emotionally withdrawn, making it difficult for them “bond.” Some mothers of the higher functioning children in this study reported that they were able to “interact” and “connect” with their child. However, the mothers of lower functioning children struggled to connect with children who were “withdrawn,” “nonresponsive,” “can’t stand to be touched,” and “could care less about their family.” In this mother’s story, her guarded optimism is evident, and her desire to make contact with her son profound:

We are in the hard place now, because we are in the transition. But some days, he really wants to be with us, to help us, and he… It's not all the time, but you can see moments that he really enjoys [us] and that he had us, you know? (ID #11)

All the mothers felt acutely the impact that their child’s exclusion from others would have on their ability to be part of society and, in turn, their child’s future. They struggled to find ways to belong: “I think the hardest thing for me is that you don’t fit in anywhere; you’re always trying to fit in where you don’t. You’re always going against resistance” (ID #3). Although all of the mothers felt the emotional impact that the isolation and the stress of parenting their child with autism produced, their primary concern was for their child. While they all acknowledged that there were difficulties that accompanied parenting a child with autism, they perceived
themselves to have a responsibility to parent their child and that meant continuing to move forward. One mother described her experience: “You turn yourself off, it's okay. I've had a couple of breakdowns, I'm not going to lie, but yeah, you're the mother, pick yourself up” (ID #8). Another had this to say: “There's a sacrifice whether you like it or not. Your lives change when you have a child with a disability, but we're careful not to be stretched so thin that now we're all a mess” (ID #7).

The three decision-making processes -- searching for answers, nothing we can do, and making a choice – that are captured in the fighting from the fringe core concept exist within this context of stress and isolation. How these three processes contributed to the decision-making process to use CAM will be demonstrated in the following sections.

3.2 Searching for Answers

The first step in the decision-making process for CAM was the diagnostic process where mothers struggled to find answers about the cause(s) of the symptoms and behaviours their children exhibited. In this step of the process, the mothers began to feel disenfranchised from the conventional health care system, a development that had a significant influence on their decision to use CAM.

3.2.1 “Something is not right.” The mothers all recognized something was wrong with their child early on, usually between 1-2 years of age, although one mother noticed as young as 2 months that her child’s behaviour was unusual. The behaviours their children demonstrated and the physical symptoms they suffered from were present prior to obtaining an official diagnosis of autism. Various symptoms, such as chronic GI issues, diarrhea, vomiting, and concerns about appetite, lack of speech, apparent deafness, and being “zoned out,” prompted the contact with a conventional health care practitioner. Usually, this was the family doctor, but it also included
also infant development team members, public health nurses, and speech language therapists.

Some mothers were also motivated to take their child to a physician because of more ambiguous feelings that “something is wrong” or “something is off.” Many of the mothers, however, reported that their initial concerns were dismissed by physicians, particularly if the child was young and the symptoms of autism not yet clearly apparent. The majority of the mothers told stories of a continuous cycle of misdiagnosis, dismissal of symptoms, and how their distress over their child’s behaviors was not being heard or acknowledged:

> We found that it's really hard. First of all, you're waiting to get in for testing in a traditional medical system. The doctors are very busy so we have a limited amount of time for information to be exchanged, and a lot of times you just… you feel like you're not being heard, like you're being brushed aside. "Oh, yeah, yeah, yeah, okay. Okay, well, that's normal." (ID #15)

The disregard of their apprehensions about their children played a pivotal role in the mothers’ disengagement from the conventional health care system. All of the mothers reported feeling frustrated instead of reassured that their concerns were being ignored. Healthcare providers were no longer people they could work with to understand what was happening with their children; rather, they were people they needed to fight against to get answers. This conflict led many of the mothers to begin to doubt their conventional doctors’ abilities, a doubt that would continue to grow as the diagnostic process went on. It is important to note that it was between the suspicion of autism and the “official diagnosis” that many of the mothers started to engage in the information-seeking process, an action that would occur throughout the various decision-making processes described in the core construct: “Even before getting the diagnosis I’d been reading up a lot right, so I kind of know what is out there” (ID #2). Mothers were beginning to attempt to educate themselves not only about what autism was, but also what could be done about it.
3.2.2 Seeking a diagnosis. For many of the families, repeated visits to family doctors and pediatricians were necessary before a diagnosis of autism was made. Subsequent to this preliminary diagnosis, parents still needed to have further testing done by the British Columbia Autism Assessment Network (BCAAN) or a private clinic that adhered to the diagnostic criteria of the BCAAN to qualify for the funding that the Ministry of Children and Families provided for treatment. The Autism Spectrum Disorder clinical pathway requirements set by the BCAAN for a diagnosis of autism are complex and it is often a lengthy process. For a few families in the study, their children were diagnosed quickly; but, for many of the children, the wait to be diagnosed was protracted. On average, the wait for an official diagnosis, once the initial suspicion of autism was confirmed by a family doctor or pediatrician, was 6-12 months. Two mothers, of higher functioning verbal children, told of their sons’ diagnostic processes that took years. Several mothers found the waiting period between possible diagnosis and official diagnosis to be intolerable and opted to pay for private diagnosis at a great financial cost.

The exact timelines and diagnostic processes varied between families but the experience was universal. Following the diagnosis of autism the mothers spoke of being “devastated” by the loss of their “normal” child and their dreams for their child: “…when he first was diagnosed I'm like lying in bed just sobbing, ‘I want him to be married and have kids” (ID #14) and of feeling “powerless”:

"What happens?" It's brutal. It is absolutely brutal. And I found that when… I came home paralyzed, not because I was… First of all you have to deal with the diagnosis and the impact that has. You're dreaming what could be… you're dreaming your own dreams for your child. You're dreaming the future with your child. You're dreaming… you're thinking, "Okay, we're never going to get to do this. We're never… I thought we'd be doing this by the time he was eight. Well, that ain't going to happen" (ID #15).

3.2.3 Nothing you can do. For many mothers, the prognosis given to them by their doctors was bleak. They were told their children would “never talk,” “use diapers forever,” and
“never live independently,” and that there were limited treatment options available beyond intensive education interventions. One mother recalled what she was told by her doctor following her son’s diagnosis: “He literally was saying, ‘He'll be in an institution. He'll never talk. He'll never get married. He'll never have children. There is nothing you can do’” (ID #5). For a small number of mothers whose sons were diagnosed at a later age and were verbal and higher functioning, the prognosis was not as grim; however, all of the mothers were told there was little they could do and to abandon or at least limit their hopes for their child’s future.

The mothers in the study easily recalled the anguish of getting their child’s diagnosis but they did not focus on this period in their life. Most of the mothers had children who had been diagnosed several years previous to this study, with only three children diagnosed in the last two years. As a consequence, all of the mothers had moved past the initial devastation of the diagnosis and instead focused on what they did following it. As one mother shared, “I remember feeling powerless for a little while, but then I just, you know, took charge, I guess it would depend on how long that powerless feeling lasted, so you'd kind of fall into, ‘Well, I have to do something’” (ID #11). They described how they began to move forward and sought information to figure out what they could do to help their children:

I was sad. I think that it's quite normal that you feel sad about it because it is something that you're not expecting. But being sad all the time is not going to help. And so I say, "Well, what else we can do? We have to face it. It's just how it is. It's not a dream, its reality, so now we need to see what we can do.” (ID #12)

The mothers’ information-seeking and decision-making processes for various CAM treatment options intersected with those decision-making processes for educational interventions. The data did not allow the individual processes to be separated out; therefore, explanation of how conventional intensive educational interventions were chosen is included.
While there is no cure for autism, there are conventional educational interventions that have been shown to benefit children with autism to varying degrees. Once the official diagnosis was made, parents were referred by the BCAAN or their private practitioner to the Ministry of Children and Family Development (MCFD). The MCFD provides autism funding for various intervention services. The list of eligible services was provided to parents along with the Registry of Autism Service Providers and it was left up to the parents to select behaviour consultants, physiotherapists, speech language pathologists, and occupational therapists. The MCFD provided a comprehensive handbook for the parents but then left the responsibility of finding and assessing expertise and fit, as well as hiring autism service providers, to the parents. The parents were also responsible for the setup, monitoring, and implementation of their child’s care plan for their child. While the MCFD did provide funding for treatment, it was universally agreed that it did not completely cover the high cost of the prescribed educational interventions, with parents having to cover the remaining expenses.

Most of the mothers in this study commenced an educational treatment program. The majority of the mothers who did choose this type of treatment program believed that their children’s autistic symptoms would be improved. The mothers who chose not to use a educational treatment approach had older, higher functioning, verbal children who were diagnosed at a later age; thus they did not feel their children would benefit from these interventions. A small number of mothers started educational treatments, but at the time of the study had ceased to use them as they felt the treatment methods were not a good fit with their child and had not achieved the results they wanted.

The mothers who did choose educational treatments found the decision-making process overwhelming, confusing and expressed their frustration at the lack of guidance and support
available to them in this process. The absence of any meaningful assistance in this process
obligated parents to make choices they did not feel they had the expertise or qualifications to
make:

I'd say in the first six months, you feel like you're under a gun, because you're… you
don't know what to do, so you're just feel like you can't make decisions fast enough or
quality enough. And then are you doing the right thing and no one's there to say… yeah.
(ID #7)

3.3 Identifying Goals

Educational treatment did offer the possibility of improvement in the areas of
communication, behaviour, and social skills; however, it did not address all of the concerns that
often accompanied autism but were not considered part of the diagnostic criteria. Which
particular conditions mothers sought relief for varied between individuals; however, an
improvement in behavioural issues, communication, and social deficits was the goal of the
majority of mothers. The mothers desired an increase in their child’s ability to learn, to appear
“normal,” and to fit into the world:

So to me dealing with those underlying issues, whether they be dealt with through
supplementation, getting some blood work done, changing some diet, you're not just
going to improve that child's physical wellbeing, but you're also going to improve their
quality of life and their ability to learn and integrate. (ID #15)

Most of the mothers felt that their children would always have autism and so their goal of
treatment was not a cure but to help improve their child’s quality of life and improve their ability
to function in society:

If he can cut down on the aggression, then he's not going to hurt himself or hurt anybody
else. If we can do that, all of these things, then he's probably more likely to be
comfortable and feel better in his own skin. If he's able to adapt, he's going to be better
able to socialize and get friends and have a quality of life, he's going to be able to
normalize, self-regulate. Just it opens up a huge amount for him. We've already seen that.
(ID #15)
For a small number of mothers, their goal was loftier -- to cure their child of autism. This goal would lead them try the greatest number of CAM therapies, including more experimental and extreme therapies. While this hope of a cure may have existed for all the parents in the study, when asked, the majority of the mothers stated their goals were more pragmatic.

Having their child “written off” was unacceptable to these mothers, for whom doing nothing was not an option: “the traditional medical community seems to be giving me the impression that if you have autism, there’s no cure and there’s really nothing else, so I want to see if that is true – nothing else” (ID #2). Dissatisfied with their conventional health practitioners’ response to their concerns, the mothers continued to seek information and look for answers on their own. All of the mothers talked of spending hours doing research about both conventional treatments and CAM therapies in an attempt to try and find answers and solutions to their child’s autism.

3.4 Looking for Alternatives

Once the definitive diagnosis of autism was obtained and the limitations of conventional therapy reached, the mothers became more determined in their search for information about treatment options and potential positive outcomes. It is important to note that the mothers’ information-seeking behaviour occurred throughout all three processes in the ‘fighting from the fringe’ construct. The sources of information outlined in the following section focus specifically on seeking CAM information

3.4.1 Sources of information

"I need to know what to do, I need somebody to tell me what to do." (ID #15)
Anecdotal Evidence. Families accessed a range of information sources; however, for a majority of the mothers, their information was obtained from the Internet and from books written by other parents. These sources of information had parents chronicling their experience of living with autism and how they used various treatments to improve their child’s condition, often with astounding, encouraging results. One mother who had chosen some of the most unconventional treatments in the study was unguarded about where she found out about them: “Oh my gosh! Where did I find out about that? Just the Internet, reading it” (ID #10). This was where a majority of the mothers became exposed to the potential CAM options available to treat autism. An exception was one highly educated mother who had access to a large academic library and relied on scientific journals to find information on CAM. For a few mothers, the anecdotal evidence of other “expert” parents was not considered to be rigorous enough and trustworthy; they desired scientific, researched, or professional opinions. As one mother shared:

Well, you know, like parents are so … like they are feeling so desperate, whatever comes, maybe if you give them a placebo like water, and you say, ”This is good medicine for autism,” they will give it and say, ”Yes, that works.” You're not sure. Not all parents are the same – there are lots who are optimistic. And sometimes we don't… like in our minds, it's not equal, we don't logically think about things. This is why I need to make myself sure before I start any therapy, supplements, or whatever. (ID #13)

The majority of mothers looked to a variety of sources for information; one mother described her information-seeking process in the following manner:

If it intuitively seems like it'll make sense, that's my first green light to go to the next step, which is then look it up and do some research on it. Talk to other people. If that looks okay and makes sense, and those first step one, the intuitive and step two, there's some sort of information there that shows maybe there's a link between that and, say, allergies, or that and gut issues, or a deficiency somewhere or a study has shown… a medical study, and there's a couple of others that point to similar things, then that's my second green light. Then the third one is… my third checkpoint after I've done those, is it going to harm him in any way? Is there going to be any negative effect if we try this? (ID #15)
What all the mothers interviewed valued was that other parents not only shared treatment information, but also were acquainted with the experience of having an autistic child, something that was extremely important because other parents “got it.” Whether they utilized the information from other parents or not, this shared understanding alleviated some of their isolation and stigmatization that comes from having a child with autism. A few of the mothers in the study had negative experiences with other parents who felt that CAM was not a viable treatment option. These mothers found that some parents in the autism community adhered to a stringent behavioral interventional treatment-only perspective and were extremely dismissive of CAM. This reaction from behavioral-only proponents further exacerbated these parents’ sense of isolation and stigmatized their decision to use CAM. These parents, however, were able to dismiss this response by finding other parents who shared their views and validated their choices.

*Advice from Conventional Medicine.* Despite the use of anecdotal sources of information, all the mothers expressed a desire to also obtain expert advice on their decision-making process. Many of the mothers also valued books as sources of information, primarily those that were written by doctors (mostly psychiatrists and psychologists) and those they trusted to have extraordinary knowledge about autism and treatments. Several of the mothers also reported attending autism workshops and conferences presented by experts in the autism field to increase their knowledge about autism research and treatments.

The mothers were able to find volumes of information about CAM treatments from a variety of sources; however, many spoke about their feelings of inadequacy when it came to understanding the credibility of the information they were finding and being overwhelmed by the amount of research. Much of the information they found was conflicting, the sources questionable, the research language difficult to understand, and the number of options
overwhelming. As a result, many of the mothers sought advice from their physicians about the CAM therapies they were considering for their children in the hopes of gaining a credible and professional perspective:

I actually brought in with me two books written by medical doctors on autism and biomedical [treatments], and the difference they see working with their kids who are in the States. They're quoting scientific journals, like Lancet. They're not quoting some autism science digest or something. They're quoting actual medical peer-reviewed review studies. She [the pediatrician] wouldn't even look at them. And I'm like, "But a doctor wrote that. It's peer-reviewed. Look at… there's like an index, study after study after study." And she wouldn't even look at it. (ID #15)

Unfortunately, the many mothers who sought a partnership with their conventional health practitioners in the CAM decision-making process experienced similar responses of dismal and derision. They talked about dealing with the “disgust on their doctors faces,” “doctor think[s] you're nuts,” “they [doctor] will think you are crazy,” and “[being told] I was wasting my time.”

The refusal of conventional healthcare practitioners to engage in dialogue about CAM or consider CAM as a viable option for autism treatment pushed these mothers further away from the conventional healthcare system and, for many, was the final step in their disenfranchisement from conventional care. The disregard of conventional practitioners for the mothers’ needs for information and advice, the condescension towards the work and research the mothers had undertaken, and the indifference to the mothers’ appeal for a partner in the decision-making process were particularly egregious for mothers who had been left alone to find answers.

Wait a minute. If a parent of a child with autism is interested enough to do all of this reading, all of this study, taking courses, going to workshops, going to lectures, doing the reading, getting books out, spending hours on the internet researching, talking to other parents, is like pretty savvy, then there's a way you can explain it to me. I will get it. Even if you have to explain it to me like I'm two years old, I will get it. (ID #15)

A small number of the mothers, however, had very different experiences when approaching their conventional healthcare providers:
So I talked to my psychiatrist at the time and he was quite open-minded. He said, "If I were you, I would try." He said, "You never know." He said, "Chinese herbs or medication may not be proven scientifically, but it comes with thousands years of experience." He said, "You can try." (ID #6)

While some of the mothers also had positive experiences with their conventional health care practitioners, a void of treatment options still existed. Interestingly, despite their positive relationships, these mothers did not care if their conventional health care practitioners supported their CAM choices or not. A lengthy, cyclical pattern of misdiagnosis and dismissed concerns by conventional medicine during the diagnostic experience had left the mothers unconvinced about conventional medicine’s ability or desire to help them and their child: “After that, I started really researching because I thought, ’They don't know what the hell they're doing’” (ID #4). In the absence of support from conventional medicine for CAM, parents began to seek expertise elsewhere: “Well, the doctor at Children's did me a big favour because he said, "There's nothing we can do." So I thought, "Okay, well there's nothing you can do. I'm going to go find someone else who can do something” (ID #5).

**CAM Providers.** For CAM expertise, the mothers sought out doctors of naturopathic medicine or traditional Chinese medicine practitioners to provide information and to partner with them in their decision-making about CAM, even though many had already started using some CAM. Many of the mothers saw the same naturopath who not only specialized in treating autism, but had an autistic child herself. This level of expertise about autism, both professionally and personally, was highly valued by the mothers: “I found a lot of them [naturopaths], but I liked her because she has a son with autism too” (ID #11).

Partnerships developed between the mothers and complementary and alternative health practitioners who not only listened to their thoughts and concerns, but offered them alternatives and provide information that would help in the decision-making process. These complementary
and alternative health practitioners were also perceived to support the mothers’ choices in a non-judgemental way, validating their capacity as parents to make good and meaningful choices for their children. While the mothers valued their various alternative healthcare practitioners’ expertise about CAM, they did not capitulate their role as primary decision makers to them. This was a change for many of the mothers from how they had made treatment choices in the past with their conventional doctor. As one mother shared: “Yeah, I've always just done what my doctor says. I've never, ever questioned anything” (ID #14). Now, however, the mothers perceived themselves to be the experts on their children’s needs and care:

"We're not going in to say, "Okay, he's got this, this and this. What do we do?" That's how it started, but now it's sort of as we've sort of become more educated, we self-educated ourselves, we're doing more of the research, more of the looking at stuff. We're looking at our son’s behaviour because we live with him, looking at where he's at, how he's behaving, what we could maybe do to compensate. (ID #15)"

3.4.2 Factors that influenced the use of CAM. Mothers’ communicated many factors that influenced their decision to use CAM. This section explores the most common considerations and the impact on the mothers’ decision-making processes.

Emotions, personal beliefs, values, and “intuition” or “gut feelings” were considered by a significant number of the mothers as a reliable way to make decisions for their children. If it felt right for their child, and felt right to them, they were likely to choose a CAM treatment as a viable option. This mother explained as follows: “And it's going to sound a little crazy, but it's sort of more of an inner voice thing. You have to just sort of listen to yourself. And I do that on a regular basis” (ID #8).

Almost all of the mothers reported assessing the CAM therapies they were considering for “fit” with their family, aligning with their personal beliefs and values. For example, one mother shared the following reflection on the CAM selection process:
And I just felt, I don't know, from the beginning I just did not… when I read it, I was like, "This doesn't fit my kid"…. but I wanted… every mother wants to… I just didn't feel like it was the right fit for him (ID #14).

For several of the mothers in this study, one personal belief in particular played a significant role in their choice of CAM: the belief that vaccinations were wholly or partially responsible for their children’s autism. This belief, for some mothers, not only influenced their use of CAM but generated feelings of distrust and skepticism in the conventional health care system that had assured them it was safe to vaccinate their children. One mother shared the following perspective: “Because I don't even think this is autism, right? This is an injury of a vaccine. I mean that's what happened to me. I had perfectly normal children” (ID #10). Despite the overwhelming evidence that vaccinations have no direct causational links to autism (DeStefano, 2007) this idea remained firmly entrenched in the belief systems of nearly all of the mothers interviewed. While most of these mothers understood and believed that genetic factors had likely contributed to their children’s autism, they also felt that vaccinations had played a role as well.

Even the mothers who stated that they understood that vaccinations did not cause autism still had reservations about vaccinations and were not completely assured of the safety of vaccines. This mother who discontinued vaccinations in both her autistic son and her non-affected son rationalized her ambivalence in the following manner:

I don't believe that vaccines cause autism. I don't believe that you're born typical and then suddenly something…You have to have a precondition. You must. And just so you know, I will not booster my kids, and I'm not anti-vaccine, I'm not……” (ID #14)

This strongly held belief about the cause(s) of autism influenced these mothers choice of CAM, the central tenet being that because a component of the vaccine had caused autism, removal of this component with CAM could improve the symptoms and CAM
would also treat the areas affected. The belief of this causative perspective was communicated by many of the mothers and was supported by much of the CAM treatment information they accessed.

For many of the mothers, the cost of CAM therapies prevented them from trying all the therapies they were interested in using for their child. “It cost me so much money, and that was really hard. It was almost $1,000, and all out of my pocket. And that's really hard for me. You know, I'm a renter and I'm a single mom” (ID #4). This experience of limiting and even discontinuing CAM therapies because of cost was almost universal amongst the mothers. The mothers also spoke of cost in personal terms. The expense of attempting and maintaining these therapies meant they had to make sacrifices in other areas, including their ability to work outside the home, transportation and time spent with their “normal’ children, spouses and friends. This mother shared her position, “I mean we don't do holidays, we don't do… You know, our other son is limited in what he can do… So we've sacrificed because we've been able to afford to sacrifice” (ID #1).

The majority of the mothers also said they assessed CAM therapies for their potential to cause harm or discomfort to their child. Most of the mothers did choose well utilized and more mainstream CAM therapies; however, a few of the mothers were willing to try less well known or more novel therapies. Interestingly, a small number of mothers who did not engage in an assessment of risk to their children when selecting a CAM therapy were also the mothers whose goal of using CAM was to cure autism in their children. Risk tolerance varied from mother to mother and no universal level of acceptable harm or discomfort was determined.

Very important to the mothers in the study was the credibility of the source of information. As noted earlier, many mothers looked to anecdotal evidence from other parents to
provide essential information about CAM treatments; in their eyes, other parents’ knowledge and experience with autism made them credible experts. Also considered to be a highly credible source of information about CAM by all of the mothers was their naturopathic physician or other alternative health practitioner. While the mothers had initially returned to their conventional healthcare practitioners for advice, following their disenfranchisement from the conventional healthcare system, none of the mothers felt that they were a credible or reliable source of information about CAM. Physicians’ reluctance to engage in a dialogue and lack of knowledge about CAM made these parents question their expertise in this area. The mothers did, however, value books and information provided by physicians, psychologists, and other practitioners with experience in autism. Mothers saw these conventional healthcare practitioners as a credible source of CAM information, suggesting a personal bias on the part of the mothers towards those conventional healthcare practitioners whose beliefs aligned with theirs.

The mothers’ personal experiences with CAM were also a factor in their consideration to use CAM. The mothers used their CAM experience in two ways. Certain mothers had personal experience with CAM use prior to trying it with their child and so, were already familiar and comfortable with this type of treatment. These mothers reported feeling comfortable with CAM and already had confidence that these treatments would be effective. The other way that experience was a factor was their successful use of CAM. All of the mothers stated they saw improvement in their child’s health and behaviours with the use of CAM, and this success encouraged them to try other CAM therapies, as this mother explained: “I had read about the diet being the number one, and it worked so well immediately that I just kept reading what I was reading. When I learned about the diet helping him, I just kept going” (ID #4).
For a small number of the mothers, their personal social network was also an influence in their use of CAM. Family members would suggest and encourage certain CAM therapies and their endorsement would be enough for these parents to try them. Interestingly, certain mothers reported being discouraged, often vigorously, from trying CAM by family members. These mothers found this experience to be distressing and isolating; however, their family’s opposition seemed to do little to dissuade them from using CAM, as this mother explained:

And everyone, my family, everyone disagreed with me. And still I have members of my family that think I’m crazy for the diet. … First of all, I’m very aggressive, so no one is going to in my family challenge me because they won't see me kids. Like it's horribly immature, but I don't have the energy. (ID #14)

The particular factors used by the mothers to evaluate the treatment options varied between individuals. The data were examined to identify if individual characteristics, such as the number of children affected by autism, the age of the children, years since diagnosis, ethnicity of the mothers and the goals of therapy, had any influence on the factors utilized in the decision-making process. There did not appear to be any relationship between the characteristics of the mothers and factors used to filter CAM choices.

Once all the possible CAM therapies were assessed and the various factors considered, parents then proceeded to the next phase in the decision-making process, actually selecting a CAM therapy for their children.

3.4 Making a Choice

“You’ve made that choice. You had to make a choice.” (ID #4)

Stressed and isolated as a consequence of parenting an autistic child, distrustful of the conventional healthcare system, and devastated by the autism diagnosis, the mothers fought to find options to help their children. They progressed from conventional medicine to the fringes of
healthcare, by seeking complementary and alternative healthcare practices, discovering and considering sources of information, identifying their goals, and filtering treatment options through influencing factors. Equipped with possible CAM treatment options the mothers now entered the final process in the fighting from the fringe construct: making a choice.

For the mothers in this study, a burden of choice was imposed on them by the lack of information about the cause of autism and possible treatments options. Mothers felt disenfranchised and lost; a lack of direction and support from conventional medicine meant that they alone were responsible for making a choice about their child’s treatment and plan of care. As one mother shared: “So you're being forced to make choices that you don't necessarily want to make or have the knowledge base to make those” (ID #7). This burden of choice compounded the existing feelings of stress and isolation. Adding to this pressure, mothers also talked about the overwhelming sense that not only did they have to make a decision alone, they had to make it quickly even though they felt uninformed and unqualified to do so. The mothers had learned from their research that starting treatments at as early an age as possible was linked to potentially better the outcomes for their child. One mother explained the immense pressure that making a choice, the right choice, placed on her:

No, so you have to go with something. You can't delay your option… your option in making that choice, because you're told to get on it, get on it, get on it. And you want to get on it, because you want to help your child. So you make the choice, then you're pinning your hopes on that choice. You're pinning your future for your child on that choice, which is a huge responsibility… a huge sense of responsibility, I should say, which comes with a load of a tremendous amount of guilt and worry and fear and all of that. And then, not only that, but then you start to question that choice, unless… if you don't see perfect progress, or you don't see this, or you see a child's not liking it, or it's been a bad day. It doesn’t even matter if I didn't do therapy if it's been a bad day, then you start to question that choice. Then you feel guilty, then you need to defend it, because you're already pinned all those hopes on it. (ID #15)
Despite many mothers’ anxiety at having to make the choice alone, all of them did make a choice to use CAM. The mothers were asked to fill out a questionnaire (Appendix F) prior to the interview about which CAM(s) they had used and would like to use. A complete list of the CAM therapies being used, no longer used, and those being considered is available in Appendix J. Over half of the mothers were candid when they revealed that the choice to try a particular CAM therapy was not only based on whether they thought it would work, but rather based on the hope that it would. Because there was no way of knowing which treatments would work for their children, these parents wanted to feel like they did all they could to help their child by pursuing every option. One mother explained her rationale: “The guilt, I would say that I do all these things because I'm not going to look back and say, ‘Oh, I should have done that.’ Leave no stone unturned. I don't think that drive is a negative drive” (ID #8). The avoidance of guilt was a powerful motivator to try a number of CAM therapies: “In the future, when I see back, I can say, ‘Okay, I did everything I could” (ID #11).

3.5 Evaluation

The primary way that parents evaluated their choice of CAM therapy was whether or not it addressed the particular concern they had about their child’s behaviour or health. Despite the variation in the types of CAM tried between families, all of the mother’s reported that they felt the CAM therapies they had chosen were working to improve their child’s behaviour and overall health. The data did not allow for the determination of specific time frames for the children’s progress, although many mothers told of improvements that happened within days to weeks of trying CAM. The mothers used language such as “hugely helpful,” “amazing,” “it's working for him,” and “we are on the right track.” They also shared very specific stories of their successes in areas such as communication:
He went immediately from saying, "Juice," to, "Want more juice, please" – immediately sentences and more comprehension and cognition, and everything better instantly. So from there I just knew that it was going to be what we could do." (ID #4)

Many mothers reported success with the elimination of gastrointestinal issues, improvements in sleep, decrease in problem behaviours, improvements in dermatological conditions, decreased hypersensitivity, and improvements in social functioning:

She wasn't very social at home, like she wouldn't greet people, she wouldn't say hello, and that is the one thing that was fixed. She was more interested in her peers in the class and she would actually say hello to an adult – like, "Oh, hi, G," and that kind of thing. It made her a whole lot more social. (ID #10)

The mothers reported that they were not the only ones who saw the results. Positive feedback from people outside the family that their child was improving was also very valuable to them and confirmed that they had made an appropriate choice. The children’s symptoms and behaviours were improved from the mother’s perspective and from the perspective of others. As a result, the mothers perceived the claims made about the CAM therapies their child was using were valid. Even though their initial goals -- the improvement of behavioral issues, communication, and social deficits and the desire to see an increase in their ability to learn and appear “normal” were not fully realized – the mothers were not discouraged as they saw the treatment as an ongoing process;

You know what? I honestly believe, and I'm not a fool, I'm not in denial, I think there comes a point, as they get older and older, there comes a point where you're just like, ‘You know what? L. is L., and L. is awesome. And let's just let him be happy and do the best we can for him in non-invasive, non-risk, non-painful ways, and it will be what it will be.’ (ID #8)

Despite their successes, many of the mothers reported a conflict in their fight; their desire to fit in and have their child fit in were juxtaposed by having to make treatment choices that exist on the fringes of healthcare. As one mother shared: “…and every single thing I've done on the natural route, I've had to really fight for” (ID #14). They were reluctant to tell people about the
CAM treatments they had chosen and the success they had experienced for fear of condemnation. This experience is evident in one mother’s story of her success in finally getting her child to sleep through the night after 9 years of chronic sleep deprivation: “But would I tell that, would I shout that out to the world with the abuse that I've been given over the years? Not on your life” (ID #1). She was successful in obtaining a solution to a problem that had plagued her child and her family for years, and yet the shame and the stigma associated with her choice meant she had learned to keep quiet.

Ultimately, all the mothers felt their fight was worth it. Despite the opposition the mothers faced from conventional healthcare, their families, and society, they had been successful in helping their child:

I'm doing energy therapy. People laugh at me. I don't care because they told me he wasn't going to talk. So it's that, and all of that has changed. Now I don't care what anyone… Now I don't care, but at that point, I cared. If Dr. X had told me "I think this is a bad idea," I probably would have stopped. Now I won't. (ID #14)

The entire cohort of mothers reached a point where they no longer cared if others, particularly conventional health care practitioners, agreed with or approved of their choices: “I don't care what other people think and if they judge me, I think that we are making the right decision.” Despite adversity and marginalization, they would continue to fight for their children from the fringes. They made the choices that they thought would help their child and by doing so, empowered themselves and optimized a future for them both.

3.5 Conclusion

The purpose of this chapter was to elucidate the decision-making process mothers utilized in choosing CAM for their child with autism. The mothers provided narratives about their decision-making process, but also about the context within which they made their decisions.
mothers were candid about the stress and isolation that comes with raising a child with autism. The impact of mother’s disenfranchisement from the conventional health care system on the decision-making process was also demonstrated, as was its impact on their further marginalization from mainstream society. Using a grounded theory approach to analyze the data, an understanding of the process was realized. The process was not a linear one, but a complex, interrelated series of steps that mothers took to find solutions and make decisions about how to best help their children. Autism is a neurobiological disorder for which conventional healthcare can offer no definitive cause and even fewer solutions. This void was found to be intolerable by mothers who could not abide doing nothing to help their children, particularly when outside the mainstream health care system potential solutions appeared to exist. Facing opposition, the mothers in this study persevered to gain knowledge, understand the options and assess their merits through a variety of factors, develop partnerships and finally make the choices that they felt would be most advantageous for their children. From this process a core concept emerged from the mother’s experiences, “Fighting from the Fringe.”

The next chapter will discuss the implications of the findings, including a need for increased awareness of the stress and isolation experienced by mothers and additional support for families of children with autism. In addition, there are implications regarding how conventional healthcare practitioners interact with families of autistic families, including how they assess information needs and goals of treatment. The need for increased education about CAM for conventional healthcare practitioners is also highlighted by the study findings. The strengths and limitations of the research will be demonstrated and a discussion of potential applications of the research conclusions and possible research in the future based on the findings will be discussed.
Chapter 4 Discussion

In this study, a theoretical model was developed to help elucidate the decision-making process of CAM selection by parents of children with autism. This decision-making theory, “Fighting from the Fringes,” provides a way to understand the thought processes behind mother’s decisions to use CAM for their children with autism as well as how their CAM decision provided a way for them to maintain their self-identity as “good” mothers. The pivotal role of mothers’ disenfranchisement and marginalization from conventional healthcare, stigmatization within society, and stress and isolation experienced in the decision-making process will be examined further in this chapter. This final chapter will provide an overall analysis of the research and conclusions using the current available research in the field. In addition, how the theory of “Fighting from the Fringes” contributes to the decision-making field will be discussed. The significance of the findings will be described and its potential applications and possibilities for future research defined. The strengths and limitations of the research will also be discussed.

4.1 Analysis of Research Findings

4.1.1 Stress and Isolation. The mothers in this study shared what it was like to live with a child with autism, the difficulties living with autism caused and its impact on their families. An understanding of stress and isolation as the context in which the decision-making process occurs is important as it influenced the mother’s decision to use CAM. That these mothers reported high levels of stress and isolation is not surprising; a considerable amount of research focused on the challenges of raising a child with autism have found that parents, particularly mothers, have higher levels of stress than do parents of children with any other disability (Gray et al., 1992; Gray, 2001; Hastings & Johnston, 2001; Myers, Mackintosh, Goin-Kochel, 2009). Compounding the stress and isolation of living with a child with autism for these mothers was
the existence of many types of educational interventions and CAM therapies, for which there is no universal agreement amongst professionals or parents on which one will yield the optimum results. There is also minimal professional decision-making support available to parents when they are trying to decide which therapies to use (Howlin, 1998; Ogston, Mackintosh, & Meyers, 2011). Uncertainty about their child’s prognosis was intensified with conflicting reports of recovery and possible cures from “expert” parents and autism professionals. In addition, pessimistic messages about the likelihood of gaining relief from the symptoms and behaviors of autism and lack of a future for their child from conventional health care practitioners contributed to the stress surrounding autism.

The mothers found autism to be isolating to both themselves and their child; however, despite their personal needs, their primary concern was the wellbeing of their child. They understood that a child devalued and rejected by society had no future or access in the general public. This sense of isolation has been found in other studies, which have shown that mothers are aware that children with disabilities are neither accepted nor encouraged to engage in the world around them (Green, 2007; McKeever and Miller, 2004). This threat motivated the mothers to do everything they could, including exploring CAM, to try and improve their child’s chances for a future.

Despite autism’s discouraging prognosis, all the mothers in this study believed their children could change with the use of CAM and educational interventions. Research has demonstrated that mothers who see their child in a positive light and believe their autistic child can change are more likely to utilize interventions than those who did not. Further, a belief that interventions will be successful has been linked with a reduction in maternal stress levels (Dale, Jahoda & Knott, 2006; Hastings & Johnston, 2001; Stuart & McGrew, 2009). The higher levels
of hope and optimism demonstrated by the mothers in the study have been associated with less depression, more adaptive coping skills, and greater health outcomes (Ogston et al., 2011; Snyder, 2002). The investigation and use of CAM treatment options and the choice of a treatment modality that they themselves can administer may be an effective way of coping for parents and may serve as a protective factor from stress (Lecavaier et al., 2006; Osborne et al., 2007). The mothers in this study revealed that the search for treatment options was a taxing process, but having hope that the treatment choices they made would work allowed them to take on these challenges and kept them motivated (Horton & Wallander, 2001; Ogston et al., 2011; Snyder, 2002). Optimism about their child’s ability to change and their future, however, could have a negative consequence as well. Dale et al., (2006) revealed that mothers who felt that their children could be cured were the most vulnerable to claims that certain therapies could cure autism. This was demonstrated in our study with the three mothers who were seeking a cure for autism being the ones to try the most numerous or most extreme CAM choices.

It was not only their role as mothers of children with special needs that produced stress; these women also had other roles at work, within the family, and within society that generated regular stress, increasing the likelihood of being overwhelmed by additional stressful events (Ogston et al., 2011; Stuart & McGrew, 2009). The mothers in this study discussed their child’s behaviors as a source of stress for them; however, there is research that would suggest that this is a bidirectional relationship, with the mothers’ stress and isolation impacting the child and increasing their negative behaviours (Meadan, Hall, & Ebata, 2010). Alleviation, or at least mitigation, of the stress and isolation that mothers of children with autism experience is thus important as excessive stress affects not only the health and wellbeing of the mother, but of the child as well.
4.1.2 **The diagnostic process.** In a study of 1,200 families, Howlin et al., (1997) found that parents knew that something was wrong early on, and despite this knowledge, the diagnostic process was complicated and protracted. The majority of mothers in this study were frustrated by the time it took to get a diagnosis of autism for their children, particularly given their long-standing feelings that “something was not right” since their child was young. Current research found that there is often a 2-year interval between parents’ first noticing developmental delays and diagnosis (Sansosti, Lavik, & Sansosti, 2012). A Canadian study found parents saw, on average, 4.5 conventional healthcare providers and waited 3 years before a diagnosis was provided (Siklos & Kerns, 2005). Mothers who were financially able sought private diagnoses at great expense to themselves, instead of waiting for the BCAAN to diagnose their child. For other mothers, this was not an option. Goin-Kochel et al. (2006) showed that higher education and income of parents had a positive effect on how quickly a child was diagnosed; however, in a more recent study, this did not prove to be a factor (Sansosti, et al., 2012). Regardless, parents from lower socioeconomic backgrounds may have less access to resources and protracted wait times for diagnostic services. Ensuring that all parents have equitable access to timely services is crucial.

Mothers also expressed their exasperation at not being listened to and having their concerns dismissed, and by the convoluted and circuitous diagnostic process itself. These findings are reflected in previous studies that have shown that getting a diagnosis of autism to be one of the most stressful times for parents (Baxter, Cummins, & Polak, 1995; Goin-Kochel, et al., 2006). The literature has similarly demonstrated that parents experience a high degree of stress when dealing with conventional health care practitioners during the diagnostic period, particular around communication (Goin-Kochel et al., 2006, Howlin et al., 1997). Goin-Kochel
et al. (2006) noted there is a tendency for conventional healthcare practitioners to minimize or dismiss parents’ concerns. The acknowledgement of parents’ initial concerns and an earlier and faster diagnosis of autism are associated with reduced parental stress (Brogan & Knussen, 2003; Mansell & Morris 2004). Goin-Kochel et al. (2006) found that the fewer healthcare professionals the parents needed to see to get a diagnosis, the more satisfied they were with the diagnostic process. Conversely, when conventional healthcare providers met parents’ concerns with indifference during the diagnostic process, parents reported feeling anger, frustration, and a lack of trust in the health care provider and the information they provided (Brogan et al., 2003; Gray, Msall, & Msall, 2008; Howlin et al., 1997; Mansell et al., 2004; Sansosti et al., 2012). The prolonged and frustrating diagnostic process caused the mothers in this study to become distrustful of conventional medicine, and its inability to provide answers and was the first step in their disenfranchisement from the conventional healthcare system. Interactions that are particularly stressful and adversarial have been suggested to even have a negative impact on the success of education interventions in the future (Osborne, McHugh, Saunders, & Reed, 2007). Ultimately, a protracted diagnostic process increases parental stress and affects their ability to cope with the disorder. It also limits the child’s eligibility and access to early intervention, which may increase the likelihood of better outcomes (Eikeseth, 2009; Goin & Myers, 2004; Sansosti et al., 2012).

4.1.3 Disenfranchisement from the healthcare system. The results of this study illuminated the issue of maternal disenfranchisement from the conventional healthcare system. This experience appears to have had a direct influence on the mothers’ choice to use CAM. It also had an impact on conventional healthcare providers’ ability to monitor and participate in the health and wellbeing of the families and children in their care, an issue that health care providers
need to be aware of and endeavour to make reparations to if their clients’ best interests are to be served.

The current research elucidates why this phenomenon occurred by examining the relationship between professional service providers and mothers of children with various disabilities. The primary role of these relationships is to benefit the families and to provide service and guidance; however, these relationships are often perceived by mothers as threatening to their self-identity, predominantly in their role of mother (Todd & Jones, 2003; Ryan & Runswick Cole, 2008). Particularly problematic in this relationship between conventional healthcare providers and parents of children with disabilities is the inequity of power and the contradictory and inconsistent information about treatments (Todd et al., 2003). These power inequities are obstacles to obtaining services, leading to resistance by the mothers of children with disabilities and causing them to challenge the authority of the service provider.

All of the mothers in this study experienced negative interactions with conventional healthcare practitioners, causing them to become disenfranchised from the conventional health care system, some to a greater degree than others. These problematic encounters with health professionals started early in the diagnostic process and had long-term effects on how they felt about their relationship with the conventional healthcare system as a whole. The mothers reported having to fight to have their experience, competency, and expertise about their child recognized and valued by health professionals. The mothers wanted to avoid being labelled as desperate, illogical or “one of those mothers” by their conventional health care providers, finding these judgements to be disempowering -- results that are consistent with other studies (Ryan & et al., 2008). Todd et al., (2003) demonstrated that mothers wanted their motivations for seeking help to be seen by health professionals as being driven by their need to help their children and
not out of some sort of pathological delusions. The mothers in these comparative studies struggled to have their role as a good mother affirmed by conventional healthcare practitioners, particularly when they viewed challenging the professional voice as an expression of motherhood and when the well-being of their children was a stake (Todd et al., 2003). This is evidenced in this study by the mother’s rejection of their conventional health care provider’s prognoses for their children, which made some mothers feel like they were being asked to reject or abandon their child. Their determination to choose an unconventional treatment path, despite the dismissal of CAM as a valid treatment option, was perceived to be one of the few avenues left that allowed them to continue to care for their child.

The mothers in this study, like many mothers, felt compelled by society to uphold an idealized version of motherhood, this despite having a non-ideal child. This is an ideal that is unobtainable for most mothers, and is even further out of reach for mothers of autistic children. The mothers sought treatment options to normalize their child as much as possible so they would be accepted in society. This was not only for the good of the child but also allowed the mothers to self-identify and have others identify them as a “good mother,” which was important as they often faced the stigma of being perceived as a “bad mother” when their typical-appearing child acted in a manner that disregarded social norms. These motivations likely reflected their need to “do something.” Many of the mothers spoke about “doing nothing” as not being an option -- to do nothing was to allow their child to be stigmatized, isolated, and rejected by society, and to self-identify as a “bad mother” by not doing all they could.

The mothers experienced conflict in their fight to find treatment for their children; their desire to be perceived as “good mothers” by healthcare professionals and society and have their children fit in was juxtaposed by treatment choices consigned to the fringes of healthcare.
However, their need to find relief from the stress and isolation of autism, to help their child, and to preserve their self-identity as a good parent was a stronger motivator to use CAM than their need for external validation of their parenting abilities. The mothers said they no longer cared what other people thought; however, their unwillingness to disclose their CAM use demonstrated a continuing need for external validation or at the very least, a desire for an absence of vilification. This contradiction is itself a stressor for the mothers. Their decision to proceed with an intervention that was controversial but that they believed would help their child is in direct conflict with their need to escape their isolation and marginalization.

4.1.3 Marginalization of parental decision-making and the burden of choice. The disenfranchisement experienced by the mothers resulted in them being solely responsible for making choices about their child’s treatment and plan of care, imposing an assumption of expertise on them that they did not have the education or preparation to hold. Compounded by the stress of diagnosis, the selection of treatments for autism is a huge responsibility and worry for parents. The choices they make may provide hope but also cause anxiety because of the concern about making the “right” choice (Blank et al., 2006; Lord, Cook, Leventhal, & Amaral, 2000). The mothers spoke about their lack of knowledge and expertise as barriers to making treatment choices for their child and expressed their concerns that they had made the “right ones.” Conventional health care practitioners need to be aware that parents who begin to have serious doubts about the efficacy of the treatments plan they have chosen may be at increased risk of stress and maladaptive behaviours (Hastings & Johnston, 2001).

The current literature reflects the findings of this study; a high proportion of parents whose children were diagnosed with autism felt they were not given any advice about treatment options or support in the decision-making process, which produced negative reactions and
excessive worry (Osborne & Reed, 2008). The mothers, lacking formal supports, were primarily self-educated about both conventional educational treatments and CAM. Not only were they dealing with a condition in which many of the non-diagnostic symptoms were not addressed, but they were making decisions about therapies that had limited evidence.

4.1.4 The role of support. A recent meta-analysis of stressors associated with autism indicated similar findings to those reported in this study; parents found lack of support to one of the biggest sources of stress (Meadan et al., 2010; Sharpe & Baker, 2007; Sharpley, Bitsika & Efremidis, 1997). This lack of support from family, healthcare professionals, and society has been associated with higher levels of stress in autistic families (Bromley, 2004); however, it was not the quantity of support that was important for the reduction of stress and anxiety but the satisfaction with the quality of support (Tobing & Glenwick, 2006).

Initially, the mothers in this study sought out professional support and advice to help understand what was wrong with their children and eventually to understand what treatment options were available. The mothers wanted to collaborate with their conventional healthcare practitioners in the decision-making process; however, their attempts to engage in a shared decision-making process with their conventional healthcare provider were denied. Even those mothers who had a positive experience with their conventional healthcare provider did not engage in shared decision-making; instead, they received the consent of their physicians to pursue other avenues of treatment. The mothers wanted professional guidance and a shared decision-making process and, when they were unable to find it within the conventional health care system, they sought decision-making support elsewhere. Most of the mothers in this study looked primarily to parent “experts” and all sought out naturopathic or alternative healthcare providers. The CAM providers offered the mothers expertise about CAM treatments and shared
decision-making, and spent time listening and validating the mothers’ concerns and issues. Previous studies that have focused on reasons for seeking out CAM providers found holism, access to treatment, empowerment, and facilitation of healthcare choices to be the main reasons (Barrett et al., 1999). Similarly, the mothers in this study felt that CAM providers saw not only the autism symptoms but endeavoured to understand the broader implications of these symptoms on the family as whole. Other studies showed that, while CAM providers did spend more time with patients, the perception from patients that they received better care was not evident (Boon, Stewart, Kennard, & Guimond, 2003). This is significantly different from the experience of the mothers in this study, who reported that the CAM providers afforded them communication, sensitivity, compassion, and treatment options that were absent in their relationship with their conventional healthcare provider. While these relationships provided decision-making support, they still desired guidance from a professional within conventional care.

Formal support groups and less structured social supports have been shown to be effective in reducing isolation and stress and improving coping (Hastings et al., 2001; Mandell & Salzer, 2007); however, the literature on formal supports shows that professional supports were the most important to parents to help them understand autism and the specific needs of their children (Siklos et al., 2006). For the mothers in this study, the lack of professional support from conventional health care providers would prove not only to be a large source of frustration, but would play a pivotal role in their decision to use CAM and to their disenfranchisement from the conventional healthcare system. Brookman-Frazee (2004) found collaborative partnerships with parents and professionals yielded more positive outcomes for a child’s behaviours and family’s quality of life. Understanding why this lack of support occurred for the mothers in this study is
crucial to improving the way conventional healthcare practitioners manage their care of families of children with autism.

4.2 Conventional Healthcare Providers and CAM

The paucity of research about the safety and efficacy of many of the CAM therapies utilized by parents of children with autism generate ethical, legal, and professional dilemmas for conventional healthcare practitioners (Cohen & Kemper, 2005). Conventional health care practitioners are limited in their ability to provide information about CAM by the paradigm in which they work, a paradigm that values scientifically-tested, evidence-based medicine. Conventional healthcare practitioners have moral, ethical, and professional imperatives to provide evidenced-based information to their patients as a way of facilitating informed consent and informed decision-making. Because it is not possible to provide evidence-based information for many CAM therapies, conventional health practitioners find themselves in a morally ambiguous position when it comes to counselling patients about CAM use (Ernst, Cohen, & Stone, 2004). Despite the perception of CAM therapies being “natural” and, therefore, safe, CAM therapies are not risk-free and, in fact, may be potentially harmful. Potential risks include toxic effects, inadequate nutrition, cessation or postponement of conventional therapies, as well as increased financial or emotional burden (American Academy of Pediatrics, Committee on Children with Disabilities, 2001; Golnik & Ireland, 2009). This risk assessment does differ somewhat in the use of CAM for autism, given that no conventional medical therapies are available and the choice to use CAM therapies may play a preventive role in the reduction of parents’ emotional burden and stress (Dale, Jahoda, & Knott, 2006; Hastings & Johnston, 2001; Stuart & McGrew, 2009).
Conventional healthcare practitioners must also deal with concerns about who is the in best position to make choices for the child. The general consensus is that parents are almost always the appropriate decision makers for their children, who do not have the capacity to make those choices for themselves, as parents know their children best, have the greatest investment in the child’s well-being, and have the most to lose if the treatment is unsuccessful (Gilmour, Harrison, Cohen, & Vohra, 2011). However, that perspective is called into question when contradictory opinions exists about the best treatment options, leading to conflicts between conventional health care providers and parents. This conflict occurs despite the research that supports the belief that parents’ desires should predominate unless the child is seen to be in danger; however, the perception of risk may vary between conventional healthcare practitioners, giving further rise to ambiguity (Hickey & Lyckholm, 2004).

When surveyed, conventional healthcare practitioners may believe that CAM therapies offer some benefit; however, they also express concerns about side effects, adverse reactions with conventional medications, and a delay in conventional treatment as reasons for not engaging in conversations about CAM with their patients (Kemper et al., 2004). Despite conventional health care practitioners’ acknowledgement of their responsibility to engage with their patients in discussions about relevant therapies, they cited lack of education, personal experience, and knowledge about CAM as barriers (Kemper et al., 2004) and expressed a desire to have additional training not only about CAM (Kemper et al., 2004) but about autism as well (Golnik, Ireland, & Wagman Borowsky, 2009). With conventional healthcare practitioners’ deficiency in education and knowledge about autism and CAM, it should not be surprising that they are more likely to feel confident inquiring about and discussing conventional medications and treatments than CAM.
4.3 Fighting From the Fringes

Many theoretical frameworks exist in the area of conventional treatment decision-making (Sirois et al., 2008); however, the lack of pediatric CAM decision-making studies and the hesitancy of generalizing research finding about adult decision-making about CAM for themselves to CAM decision-making for their children called into question the utility of existing theories (Caspi, Koithan, & Criddle, 2004). Decision-making theories and frameworks already exist that attempt to explain why and how people choose CAM therapies; however, any attempt to understand CAM use by parents of children with autism must also consider the processes of disenfranchisement, marginalization, and the need to find answers that motivate parents’ choices. They also needed to consider what parents’ expectations are regarding the outcomes of those treatments, processes that existing theories do not account for. Significant contextual differences, including the belief systems and values of parents, challenge the utility of existing theoretical frameworks to explain the processes CAM decision-making by parents of children with autism.

The research on how parents make decisions for their children’s health care is limited, particularly in CAM and autism, so the applicability of other theoretical models is problematic. Balneaves and colleagues (2007) developed the Bridging the Gap model to illustrate the failure of existing theories to consider the conflict experienced by women when trying to align two seemingly paradoxical treatment paradigms. This conceptual framework aligned with theoretical perspectives that assume that decision-making is an inherently stressful process and that a collaborative approach to decision-making that involves both healthcare providers and patients is needed. While this model does address the conflict and stress experienced when choosing CAM, the stress experienced by parents making choices for their children was different. Abandonment and disenfranchisement from conventional healthcare, intense stress and isolation, the loss of
their “ideal child,” and the absence of hope all influence parents’ decision-making. The notion that early intervention and specific CAM treatments will improve outcomes, or even cure the child, adds further pressure to parents to make “the right” treatment choice. Beliefs about the cause of autism and health care, intuition, and fit for family further influenced their decision-making. Other factors, such as cost of the treatments, experience with CAM, potential risk of injury, credibility of source, and social networks also played a role in the decision-making process.

Theoretical frameworks that depend on the decision maker to use rational and analytical thought processes assume that the individual is able to evaluate the benefits and limitations of treatment options based on evidence -- an assumption that is absent in CAM decision-making. The decision-making processes for CAM is unique from previous theoretical work focused on conventional care, primarily because of the lack of scientific evidence regarding the efficacy and safety for most CAM therapies. This has resulted in families often receiving inadequate support and outright condemnation from conventional healthcare practitioners about their inclusion of CAM in treatment plans. Past research has found parents reluctant to disclose CAM use to their conventional healthcare provider for fear of reprimand (Nichol et al., 2011; Wong et al., 2006). The mothers in this study were no different; however, it was their initial attempts at shared decision-making (SDM) with their conventional healthcare provider that established this reluctance. The mothers found it difficult to make dependable, informed healthcare choices when conventional healthcare did not acknowledge CAM. Although these mothers desired SDM, and conventional healthcare practitioners were aware of their obligations to these parents, conflicting goals of treatment and the lack of scientifically-based evidence about CAM were obstacles. The basic tenants of SDM ensure that patients are fully informed of both the benefits and risks of
their choices based on best practice evidence (Elwyn, Edwards, & Kinnersley, 1999; Légaré et al., 2008). The lack of evidence about CAM, however, makes SDM difficult, if not unfeasible. While CAM therapies remain on the fringes of health care, these differing perspectives between practitioners and patients will mean that SDM is not an option and theoretical models of SDM not applicable to choice behavior specific to CAM.

The theoretical model of “Fighting from the Fringes” moves beyond existing decision-making theories by capturing the context that is integral to mothers’ decision-making about CAM. This theory illustrates how stress and isolation impact mothers’ decision-making, and also illustrates the impact that disenfranchisement and marginalization from conventional healthcare have on the decision-making process. The “Fighting from the Fringes” theory is unique from other decision-making theories as it considers the processes of goal setting and evaluation. The mothers in this study identified which issues and symptoms were most troublesome and then identified the goals they wanted to achieve with treatment. When they found no treatments in conventional healthcare that would address all of their goals, they looked to alternative treatment options.

CAM therapies promised to fulfill many of the treatment goals they had identified. Once the mothers had chosen and used a CAM therapy, they employed an evaluation process that included feedback from the child with regard to improvements in behaviour, increased communication, and decreased social deficits. Mothers also sought feedback from people external to the family who interacted with the child. They tried many therapies, discontinued the ones they felt did not work or were cost prohibitive, and tried new ones. All of the mothers perceived CAM to be effective overall, even if their goals of treatment were not completely realized. The mothers saw CAM therapies as ongoing and, in some cases, lifelong treatments.
Despite their successes and positive attitude about CAM, the mothers remained hesitant to tell people about the CAM treatments they had chosen, for fear of further disapproval. Ultimately though, the mothers reconciled themselves to the fact that others, particularly conventional health care practitioners, were likely to disagree with their treatment choices. It may be that the mothers' decision to use CAM was part of an attempt to fulfill their maternal social role, in which a mother’s job is to provide care to her children. The mothers were unable to accept the notion that there was nothing they could do, and so they sought out treatment as a way to fulfill their role as a “good mother.” Despite adversity and marginalization, they were determined to fight for their children’s health and well-being.

Also unique to this theory is the central focus on parental decision-making on behalf of children. Other decision-making theories focus on the individual and the assumption of autonomy in decision-making. In parental decision-making, this assumption is not as clearly defined. While it is agreed by parents and healthcare professionals that children have a right to be informed, participate in decision-making, and consent and assent to treatment (Alderson, 2007; Coyne, 2006; Martenson & Fagerskiold, 2008), this is seldom the case. Consistent with the literature that children are rarely involved in the decision-making process about their health (Coyne, 2006), none of the children in this study were consulted by their mothers about the use of CAM, including two children who were verbal and had higher intellectual capacity. The decision to use CAM was made for them by their mothers with no consultation.

The central principles of pediatric health care are family-centeredness and the inclusion of children in the decision-making process regarding their health. While children have the right to be heard and participate in their care (Coyne, 2006), the ability of autistic children to make complex decisions regarding their care is questionable. The children’s ability to obtain and
understand treatment information was often absent, as was their ability to understand and give informed consent. The mothers chose CAM treatments that they believed where in the best interests of the child. A child’s intellectual deficits may limit their ability to participate in all aspects of their healthcare; however, this does not mean that they should not be considered. Autistic children’s involvement in healthcare decisions needs to be considered in collaboration with their family and health care providers (McPherson & Thorne, 2000).

The “Fighting from the Fringes” theory may provide insight into other theoretical frameworks that seek to understand parental stress and coping, as stress and coping have been demonstrated as important contexts in autism. CAM use and the decision-making around CAM is an important coping mechanism, which has been reflected in parental models of stress and coping. Modified stress and coping models such as Marshall and Long’s (2010) theory that examined the way mothers assign meaning to stressors as a way of coping, found that autism is not a stressor itself but the center of a group of stressors that interact and amass over time. The mothers reported learning everything they could about autism and its treatment and doing whatever they could to improve the symptoms of autism. These findings echoed the narratives of the mothers in this study whose use of CAM may have served as a protective factor against the stress and isolation of autism.

Balneaves et al., (1999) moved beyond traditional models of stress and coping by embedding the conflict theory model within the transactional model of stress and coping, moving away from the criticisms of rational decision-making models and allowing for the individualisation and subjective nature of the decision-making process. However, these authors still faced doubt concerning the ability of their model to measure and actualize the constructs of stress, appraisal, and coping, including the influence of social forces on individuals’ decision-
making processes (Balneaves et al., 1999). The “Fighting from the Fringes” theory gives strength to the idea that social forces have a substantial impact on the decision-making process by acknowledging the role of social networks in the decision-making process and on participants’ need to be seen as “good mothers” and how they contribute to their marginalization. The decision-making process for these mothers was complex and perhaps unique. This is certainly an area that requires further research both in the realm of autism as well as other childhood illnesses where CAM is used.

4.4 Implications for Practice

All children require a medical home that monitors growth and development identifies sensory, neurological, and health conditions that can interfere with progress, helps set comprehensive goals that optimize adaptive functioning, and advocates for proactive community programs that provide quality family supports. (Gray et al., 2008)

Despite conflicting perspectives, change is essential. Increased education to identify the early signs and symptoms of autism is needed for all conventional healthcare practitioners to decrease the interval between the time that parents report developmental concerns and receive a diagnosis. Conventional healthcare practitioners who are in contact with families of children who may be displaying autistic symptoms need to take parents’ concerns and fears seriously. They also need to educate themselves about the supports and resources available for families of children with autism to ensure that children and their families are able to access the assistance that they need and obtain services that focus not only on child but on the family as a whole (Brogan et al., 2003; Goin-Kochel et al., 2006; Mansell et al., 2004). Conventional healthcare practitioners need to understand the choices that are available, what information families are accessing, and what their treatment goals are, in order to be a gateway to appropriate health, educational, and social services provision for their patients.
The unwillingness of conventional healthcare practitioners to engage in discussions about CAM therapy options was fundamental to the mothers’ disenfranchisement. This paternalistic approach to dealing with parents is inadequate and several suggestions have been made in the literature with regard to improvements for conventional healthcare practitioners’ dealings with their patients with autism and their families. The American Academy of Pediatrics supports taking a family-centered care approach to working with families, and recommends the use of sensitive, respectful, and open communication when faced with incongruent ideas around treatments, vaccines, or beliefs about etiology (American Academy of Pediatrics, Committee on Children with Disabilities, 2001). Other recommendations for improving communication and empowering patients interested in CAM include: inquiring about the patient’s CAM use, using a respectful and non-judgmental approach to listen to the patient, understanding the patient’s reasons and goals for CAM treatment, and engaging in communication with the patient’s CAM practitioner as a way of building a multidisciplinary care team (Ben-Arye, Frenkel, & Margalit, 2004). While these recommendations may be difficult to achieve, they are necessary to improve patient care. Healthcare practitioners need to anticipate that an autism diagnosis is an extraordinarily stressful time for parents and that additional supports and services for these families may be necessary (Baxter, Cummins, & Polak, 1995; Goin-Kochel, et al., 2006). Healthcare practitioners also need to recognize that parents’ desire to try certain therapies and their belief in effectiveness of CAM are not maladaptive responses but may, in fact, moderate the effects of stress on both the parents and the child, increasing the families’ overall health and quality of life.

Conventional healthcare practitioners also need to be aware of the critical role they play following the diagnostic assessment as educators who integrate care. This is particularly true for
primary care conventional healthcare providers, who are likely to follow patients once the diagnostic team has concluded the assessment process and fulfilled their care obligations. Presently, the perception is that conventional healthcare providers’ responsibility does not extend beyond the provision of a diagnosis; however, parents want an opportunity to follow-up with their conventional healthcare practitioner once they have had time to cope with the devastation of the diagnosis and are able to absorb more information (Brogan & Knussen, 2003; Osborne & Reed, 2008). The mothers in this study were very clear that they desired a shared decision-making model; and all of them ended up partnering with alternative health care practitioners when conventional care pathways were closed to them. The study’s findings are consistent with the research that, although patients want information and treatment choice, they do not necessarily want to be solely responsible for enacting those choices (Charles, Gafni, & Whelan, 1997; Pyke-Grimm et al., 1999). The mothers in this study wanted an opportunity to ask questions at the time of diagnosis and afterwards, when they had processed the initial information and had begun to identify treatment goals. They also wanted feedback from conventional health care practitioners about the CAM treatments they selected, as part of the evaluation process. Maternal wellbeing was linked with a balance of personal control and feeling supported by those around them (Dale et al., 2006). Healthcare practitioners’ dismissal and alienation of the mothers puts them at risk of greater stress and decreased wellbeing.

What needs to change in this process is the ability of conventional healthcare practitioners to communicate with their families. Healthcare providers need to be aware that a mother’s first experience with them will determine the climate of all future encounters (Todd et al., 2003). Healthcare practitioners also need to be aware of mothers’ reluctance to discuss their own needs in terms of stress and isolation and understand that they will need to inquire after the
mothers’ wellbeing, as well as the child’s. Healthcare practitioners need to understand that a mother’s choice to use CAM is motivated not only by her need to improve her child’s situation but also by a need to preserve her identity as a “good mother.”

Healthcare professionals need to strive to maintain good relationships and communication with families, keeping an open mind and nonjudgmental approach when dealing with families of autistic children (Gilmour et al., 2011). Healthcare professionals should be knowledgeable about CAM, willing to at least discuss CAM as a treatment option, and able to educate parents about potential benefits and harms (Macklin, 1998). Healthcare practitioners need to advocate for evidence-based research for CAM to be better able to provide good quality information to their patients, helping not only their patients but themselves. Until these changes occur, children with autism, their families, and the CAM therapies they choose will remain at the margins of health care and society.

What the mothers in this study needed was information about, and access to, CAM information, parental support groups, autism professionals, coordination of services and the wanted increased education about autism for health professionals, these findings were reflected in prior research as well. Brogan et al., (2003) demonstrated that parents were happiest when they received brochures or pamphlets with written information designed to help them contend with the misinformation available from alternative sources, such as the Internet. Some countries, like Australia, have developed resources to help families of autistic children access safe, current, unbiased, and evidence-based information about treatment options for autism, including CAM. The Australian Government’s Department of Families, Housing, Community Services, and Indigenous Affairs maintains a parenting website that allows families to access information about CAM, including the amount of evidence-based research available to support claims of
efficacy and safety; the time, cost, and risk involved with using a CAM therapy; and which healthcare practitioners to consult. It does not support or dismiss the claims, but provides information. In contrast, in British Columbia, the Ministry for Children and Family Development (MCFD) provides information about accessing funding for autism treatment and service providers but does not provide any information about CAM. Similarly, ACT-Autism Community Training is a not-for-profit society that contracts with the MCFD to provide information, training, and support services to parents of children with autism. While ACT is invaluable to parents of children with autism for education, services, and care provider information, the only CAM information available is in the glossary of terms, which directs parents to various websites that may not supply the most accurate or unbiased information. What parents of children with autism need and want is access to safe, unbiased, accurate and, if possible, evidence-based information about CAM.

The development of a central online database of CAM information would also be useful in addressing the needs of families. Parents could access information about the types of CAM from current, unbiased, and -- if available -- evidence-based data. This program could run in conjunction with existing resources or independently. For example, the Australian Government’s Department of Families, Housing, Community Services and Indigenous Affairs website provides information about efficacy, safety, time, cost, and risk involved with various CAM therapies. While such a resource would require regular updating from both conventional and CAM practitioners, it would require fewer human resources to run than a face-to-face program; however, the lack of a relational interaction would still leave parents without the SDM that they desire.
The development of a program like the Complementary Medicine Education and Outcomes (CAMEO) Program may be beneficial to address the needs of families of individuals with autism in BC. CAMEO is a nurse-led research program that focuses on transforming research about CAM use for those with cancer into information that is accessible and understandable to the general public and healthcare practitioners. CAMEO examines the CAM needs of those living with cancer and develops programs and resources to meet those needs. CAMEO also provides a variety of resources, including group and on-line education courses, as well as individualized information and decision support for patients and families. While this particular program deals specifically with people suffering from cancer, a modified version of this program -- with nurses providing the same services to families of children with autism and their healthcare providers -- would address the needs addressed in this study, improving the health and wellbeing of children with autism and their families.

4.5 Limitations

All research studies have limitations and this one is no exception. This is the first study that endeavoured to understand the process of why parents of children with autism chose CAM. This study was done with a small group of participants and was limited to residents of British Columbia. While every effort was taken to include a diverse population, this study would need to be repeated with other samples of parents to fully evaluate the reliability of the results. Although it is not the purpose of grounded theory to develop theoretical models that are generalizable to everyone, further research is needed to see if the theory that was developed is useful in explaining the process for other parents. It would also be of interest to know if this theory has utility in increasing the understanding of how parents choose conventional educational therapies for their children with autism. Although the call to participate was for all
caregivers of children with autism, it was mainly mothers who volunteered and participated in this study, with the exception of two fathers who participated minimally in the information exchange. Further research that focused on fathers may demonstrate gender based differences in the decision-making process that need to be considered.

As noted earlier, the author of the current study is also the mother of a child with autism who has tried CAM in the past, although is no longer using it. This fact was revealed to all the mothers who participated in this study prior to the interview and at no point did the mothers express concern or a wish to withdraw from the study. However, this personal familiarity with the phenomenon under study may be seen as a limitation. While the personal experience of the author did pose a challenge in analysis of data, the use of bracketing and an ability to step back and differentiate the participant’s experiences from the authors was helpful in minimizing potential bias. This personal experience, however, gives the researcher a unique perspective as a nurse, an educator, and a mother of an autistic child. These perspectives allowed for a greater breadth of knowledge both empirical and personal with which to analyze the data. This personal experience may also have been useful in obtaining rich and abundant data, as the mothers who were reluctant to discuss their use of CAM and their personal experiences with conventional practitioner in a healthcare system they no longer trusted were willing to discuss it with another mother who shared their experiences or at least could understand them.

4.6 Conclusion

It was the intention of this study that a theory would emerge that would allow for a clear understanding of how parents of children with autism chose CAM therapies. By examining the narratives of the mothers who participated in the study, and utilizing a grounded theory approach to analysis the data, the “Fighting from the Fringes” model emerged. It is the expectation of the
researcher that this theory will increase awareness about the decision-making processes related to
the use of CAM by families with autistic children and enhance health care providers’
understanding of this phenomenon. Ideally, it will also influence healthcare providers to follow
the recommendations of the study and offer much needed support and education to families faced
with caring for and making treatment decisions for their autistic child.
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Appendices
## Appendix A

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</tr>
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</table>
| Antifungal treatments for yeast | May improve symptoms, some claims of a cure | • Used to reduce overgrowth of yeast that causes toxins to be released into the body.  
• May improve, confusion, hyperactivity, short attention span, lethargy, irritability, and aggression, headaches, constipation, diarrhea, distended abdomen, excessive genital touching in infants and young children, carbohydrates cravings, unpleasant odor of hair and feet, acetone smells from mouth, and skin rashes. |
| Dimethylglycine (DMG) | May improve symptoms | • May improve speech, eye contact, social behavior, and attention span. |
| Efalex oil | May improve symptoms | • May help heal a leaky gut, improve vision and fine motor skills |
| Docosahexaenoic acid (DHA) oil (Omega 3 fish oils) | May improve symptoms | • Necessary for brain development and function  
• May improve language, learning skills, gut functioning, social skills and may reduce hyperactivity |
| Flower of Sulphur | May improve symptoms | • Thought children with autism have a low level of sulfates, used for detoxification, maintaining the lining of the gut, and hormone production. |
| Probiotics | May improve symptoms | • May improve concentration and behavior, prevent overgrowth of “harmful, toxin producing” flora in the gut. |
| Magnesium & B6, B12 | May improve symptoms | • May control hyperactivity, improve overall behavior, speech, sleep patterns, decreased irritability, tantrums, improved eye contact, and learning, attention, language, speech, and brain wave activity, decrease self-stimulatory behaviour (stimming), better general health. |
| Nutritional supplements | May improve symptoms | • May improve sleep and gut function by accommodating the RDA of vitamins and minerals recommended. |
| Melatonin | May improve symptoms | • Considered to be an antioxidant vitamin. Autistic children may not make enough of it in their own bodies resulting in poor sleep patterns  
• May improve sleep |
| **Diets** | | |
| Gluten, Casein, yeast, sugar, additive and preservative free diets | May improve symptoms, some claims of a cure | • Children exhibit intolerance to many foods and/or chemicals, the main offenders being wheat, cow's milk, corn, sugar and citrus fruits. Suggested that autistic children have protein in their urine created by eating gluten and/or casein causing children to become spacey and addicted to these foods  
• May improve symptoms such as excessive thirst, excessive sweating, night sweats, low blood sugar, diarrhea, bloating, rhinitis, inability to control temperature, red face and/or ears and dark circles under the eyes, concentration, behavior, tantrums, gut issues, improve language, learning. |
<table>
<thead>
<tr>
<th>CAM</th>
<th>Claims</th>
<th>Mechanisms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Energy Therapies</td>
<td></td>
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</tbody>
</table>
| Neurofeedback              | May improve symptoms, some claims of a cure  | • Neurofeedback training involves the use of computer games to balance brain wave patterns.  
                                |                                             | • May reduce stimming, increase attention.                                      |
| Reiki                      | May improve symptoms                        | • An energy therapy that seeks to re-establishes a normal energy flow of ki (life force energy) throughout the system, improving and accelerate the body's ability to heal.  
                                |                                             | • May improve brain function, improve communication, aggressive behaviours.      |
| Acupuncture                | No claims                                   | • Not widely used in autism                                                 |
| Therapeutic Touch          | May improve symptoms                        | • Emotional and sensory regulation                                          |
| Manipulative or body-based therapy |                                             |                                                                            |
| Chiropractic medicine     | May improve symptoms                        | • Emotional and sensory regulation, may improve bladder and bowel control speech, eye contact, attention  
                                |                                             | • May reduce hyperactivity and aggressive behaviour                            |
| Cranial sacral manipulation | May improve symptoms                        | • Gentle touch is used to help balance the cerebrospinal fluid and the membranes and tissues surrounding the spine and brain.  
                                |                                             | • May increase relaxation, eye contact and verbalization.                     |
| Mind-body therapy (Not widely used in autism) |                                             |                                                                            |
| Deep-breathing exercises   | May improve symptoms                        | • Emotional and sensory regulation                                          |
| Massage                    | May improve symptoms                        | • Emotional and sensory regulation                                          |
| Osteopathic manipulation   | May improve symptoms                        | • A comprehensive spectrum of manipulative procedures are applied for the treatment of neuromusculoskeletal issues.  
                                |                                             | • May increase relaxation, eye contact and verbalization.                     |
| Progressive relaxation     | May improve symptoms                        | • Emotional and sensory regulation                                          |
| Yoga                       | May improve symptoms                        | • Emotional and sensory regulation                                          |
| Art therapy                | May improve symptoms                        | • May help with emotional and sensory regulation communication, imagination, abstract thinking, developmental deficits, visual/spatial abilities |
| Guided imagery             |                                             | • Not widely used in autism                                                 |
| Hypnosis                   |                                             | • Not widely used in autism                                                 |
| Meditation                 |                                             | • Not widely used in autism                                                 |
| Music therapy              | May improve symptoms                        | • Emotional and sensory regulation                                          |
## Whole medical systems

<table>
<thead>
<tr>
<th>CAM</th>
<th>Claims</th>
<th>Mechanisms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Homeopathic medicine</strong></td>
<td>May improve symptoms, some claims of a cure</td>
<td>• A natural form of medical care that can help children with autism in several ways, both directly as well as indirectly — such as by the use of homeopathic chelating agents that help the body remove toxic heavy metals.</td>
</tr>
<tr>
<td><strong>First Nations Medicine</strong></td>
<td>No claims</td>
<td>• Not used in autism.</td>
</tr>
<tr>
<td><strong>Naturopathic medicine</strong></td>
<td>May improve symptoms, some claims of a cure</td>
<td>• Use a variety of homeopathic and naturopathic remedies and diets that claim to improving biochemistry, brain functioning, and reversing the damage that has occurred.</td>
</tr>
<tr>
<td><strong>Traditional Chinese Medicine</strong></td>
<td>May improve symptoms</td>
<td>• May improve language, learning skills, gut functioning, social skills • Treatments is based on the belief that autism is an inborn problem of slow development of shen (spirit/brain) due to a deficiency in “original energy”, it is the restoration of this energy that is the focus of TCM</td>
</tr>
<tr>
<td><strong>Aryvedic Medicine</strong></td>
<td>May improve symptoms</td>
<td>• May improve behaviour, sensory issues, verbal skills, attention, concentration</td>
</tr>
<tr>
<td><strong>Hypobaric oxygen chamber</strong></td>
<td>May improve symptoms, some claims of a cure</td>
<td>• involves having a patient enter a pressurized chamber and breathing pure oxygen for an hour or more</td>
</tr>
<tr>
<td><strong>Chelation therapy</strong></td>
<td>May improve symptoms, some claims of a cure</td>
<td>• Used for detoxification of heavy metals such as mercury, lead, aluminum, cadmium, and arsenic. • It is thought that autistic children may not be able to excrete these metals on their own.</td>
</tr>
<tr>
<td><strong>Animal Therapy</strong></td>
<td>May improve symptoms</td>
<td>• Emotional and sensory regulation</td>
</tr>
<tr>
<td><strong>Stem cell transplant</strong></td>
<td>May improve symptoms, some claims of a cure</td>
<td>• based on stem cells ability to influence metabolism, immune system and restore damaged cells and tissues. • May improve food tolerance, gut, connectivity, behaviour, sensory issues, verbal skills, attention, concentration, self-care skills.</td>
</tr>
<tr>
<td><strong>Bone marrow transplant</strong></td>
<td>unknown</td>
<td>• Unable to find claims.</td>
</tr>
<tr>
<td><strong>B12 injections</strong></td>
<td>May improve symptoms, some claims of a cure</td>
<td>• May improve awareness, cognition, appropriateness, eye contact, speech, language, socialization, mood, tantrums, interactive play and understanding.</td>
</tr>
<tr>
<td><strong>Clay/salt baths</strong></td>
<td>May improve symptoms</td>
<td>• Used for detoxification</td>
</tr>
</tbody>
</table>
Appendix B

CAM Definitions

For this study, CAM is defined as a group of medical and health care systems, practices, and products that are not typically considered to be part of conventional medicine. These include whole medical systems, such as homeopathic and naturopathic medicine; mind-body therapies like prayer and meditation; natural product therapies that focus on vitamin, mineral, probiotics and herbal supplements; manipulative and body-based practices such as massage and chiropractic work, and energy medicine practices such as Reiki and therapeutic touch.

Biologically-based therapies
- Aloe Vera
- Antifungal treatments for yeast
- Dimethylglycine (DMG)
- Efalex oil
- Docosahexaenoic acid (DHA) oil (Omega 3 fish oils)
- Flower of Sulphur
- Magnesium
- Probiotics
- Magnesium & B6
- Magnesium & B12
- Nutritional supplements
- Melatonin
- Diets
- Gluten free diet
- Casein free diet
- Yeast free diet
- Sugar free diet
- Additive or preservative free diet

Energy therapy
- Bio feedback
- Reiki
- Acupuncture
- Therapeutic Touch
- Manipulative or body-based therapy
- Chiropractic medicine
- Cranial sacral manipulation
- Deep-breathing exercises
- Massage
- Osteopathic manipulation
- Progressive relaxation
- Yoga

Mind-body therapy
- Art therapy
- Guided imagery
- Hypnosis
- Meditation
- Music therapy

Whole medical systems
- Homeopathic medicine
- First Nations Medicine
- Naturopathic medicine
- Traditional Chinese Medicine
- Ayurvedic Medicine

Other types of complementary therapies
- Hypobaric oxygen chamber
- Chelation therapy
- Animal Therapy
## Appendix C

<table>
<thead>
<tr>
<th>Organization</th>
<th>Address</th>
<th>Phone</th>
<th>Fax</th>
<th>Email</th>
<th>Website</th>
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<tbody>
<tr>
<td><strong>ABA Learning Centre</strong></td>
<td>1110 - 6900 Graybar Road Richmond BC, V6W 0A5</td>
<td>(604) 232-4122</td>
<td>(604) 952-4006</td>
<td><a href="mailto:drsjacobsen@telus.net">drsjacobsen@telus.net</a></td>
<td><a href="http://www.abacentre.ca">www.abacentre.ca</a></td>
</tr>
<tr>
<td><strong>ABC Kids OT</strong></td>
<td>803 Fowler Court Coquitlam BC, V3J 7X2</td>
<td>(778) 355-0050</td>
<td></td>
<td></td>
<td><a href="http://www.abckids.ot.ca">www.abckids.ot.ca</a></td>
</tr>
<tr>
<td><strong>ABLE Development Clinic</strong></td>
<td>12 - 15243 91st Avenue Surrey BC, V3R 9K2</td>
<td>(604) 584-3450</td>
<td>(604) 584-3457</td>
<td></td>
<td><a href="http://www.ableclinic.ca">www.ableclinic.ca</a></td>
</tr>
<tr>
<td><strong>Coast Behaviour Analysts</strong></td>
<td>3814 West 3rd Avenue Vancouver BC, V6R 1M4</td>
<td>(604) 729-6631</td>
<td></td>
<td></td>
<td><a href="http://www.coastaba.ca">www.coastaba.ca</a></td>
</tr>
<tr>
<td><strong>Linking Autism and Families Inc</strong></td>
<td>105 - 3070 Norland Avenue Burnaby BC, V5B 3A6</td>
<td>(604) 862-5949</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Loyst and Associates Autism Services Inc.</strong></td>
<td>5002 Commercial Street Vancouver BC, V5P 3N2</td>
<td>(604) 760-6787</td>
<td>(604) 324-6337</td>
<td><a href="mailto:info@randrforautism.com">info@randrforautism.com</a></td>
<td><a href="http://www.randrforautism.com">www.randrforautism.com</a></td>
</tr>
<tr>
<td><strong>Monarch House Autism Centre</strong></td>
<td>3185 Willingdon Green Burnaby BC, V5G 4P3</td>
<td>(604) 205-9204</td>
<td></td>
<td></td>
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</tbody>
</table>

Monarch House Autism Centre provide services in English, Cantonese and Punjabi. Also serving
| Communities outside of Burnaby through satellite services. | Reach Child and Youth Development Society - ABA Program | Phone: (604) 946-6622  
Email: info@reachdevelopment.org  
Website: www.reachdevelopment.org |
|---|---|---|
| Skylark Therapy Ltd.  
Support provided in English, French & Arabic. | Unit A - 2701 Esplanade Avenue  
Port Moody  
BC, V3H 3P4 | Phone: (604) 931-8546  
Fax: (604) 931-8547  
Email: skylarktherapy@shaw.ca |
| Autism Community Training (ACT) | Suite 150 – 2250 Boundary Road, Burnaby, BC, Canada  
V5M 3Z3 | Phone:  
Toll-free: 1-866-939-5188  
Local: 604-205-5467  
Fax: 604-205-5345  
Email: info@actcommunity.net |
Appendix D
Letter of Initial Contact

Parental selection of complementary and alternative medicine for autistic children

<table>
<thead>
<tr>
<th>Principal Investigator:</th>
<th>Dr. Lynda Balneaves, Associate Professor, Nursing, UBC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-investigators:</td>
<td>Dr. Elizabeth Saewyc, Professor, Nursing</td>
</tr>
<tr>
<td></td>
<td>Dr. Pat Mirenda, Professor, Educational and Counselling</td>
</tr>
<tr>
<td></td>
<td>Psychology and Special Education</td>
</tr>
<tr>
<td></td>
<td>Ms. Tara Hodgson, Graduate Student, Nursing</td>
</tr>
</tbody>
</table>

To whom it may concern,

We are writing to request your participation in a study on how parents of children with autism come to choose complementary and alternative medicine (CAM) therapies for their children. This study is being done as part of a thesis research study by a Master’s of Nursing student, Ms. Tara Hodgson. We appreciate you taking the time to read this letter before advising us of your response.

The goal of this study is to try and understand how parents choose to use CAM therapies for their children with autism. CAM therapies are typically therapies that are not offered within conventional health care settings and include therapies such as herbal remedies, naturopathic medicine, or mind-body therapies. We plan to share our results with other researchers, health care workers and service providers to deliver better care to families of children with autism.

If you agree to take part in the study, you will be asked to fill out a survey about your child’s use of CAM; this should take about 30 minutes. You will then meet with a researcher in a quiet location, such as your home, at a time that is convenient for you, who will ask you questions about why you decided to use CAM therapies for your child. The interview will last approximately 1 hour. Your total expected time commitment to participate in this study is 2 hours.

Your participation in the study is completely voluntary and you may choose to stop participating at any time. If you decide not to volunteer, to stop participating in the study at any time and for any reason, or to choose not to answer certain questions, it will not change the health care and support you receive for your child with autism, nor your relationship with UBC either now or in the future.

If you are interested in participating or learning more about this study, please contact Ms. Tara Hodgson.

Sincerely,

Tara Hodgson, RN, BSN
Appendix E
Volunteers Wanted for a Research Study

PARENTAL SELECTION OF COMPLEMENTARY AND ALTERNATIVE MEDICINE FOR AUTISTIC CHILDREN

The goal of this study is to try and understand how parents choose to use complementary and alternative medicine (CAM) therapies for their children with autism. CAM therapies are typically therapies that are not offered within conventional health care settings and include therapies such as herbal remedies, naturopathic medicine, or mind-body therapies. We plan to share our results with other researchers, health care workers and service providers to deliver better care to families of children with autism.

To be eligible for this study you must:
- be a parent, both mothers and fathers, or guardian of a child/children with autism between the ages of 2 and 16 years who has been clinically diagnosed with autism
- have used at least one CAM therapy for their child
- live in the Lower Mainland of British Columbia
- speak and understand English

If you agree to take part in the study, you will be asked to fill out a survey about your child’s use of CAM; this should take about 30 minutes. You will then meet with a researcher in a quiet location, such as your home, at a time that is convenient for you, who will ask you questions about why you decided to use CAM therapies for your child. The interview will last no more than 1 hour. Your total expected time commitment to participate in this study is 2 hours.

If you are interested in participating or learning more about this study, please contact Ms. Tara Hodgson.
Appendix F

Demographic and CAM use Survey

The purpose of this study is to try and understand why parents choose to use complementary and alternative medicine (CAM) therapies for their children with autism. This survey asks you a few questions to help us get to know you and your child a bit better and to help us understand your complementary and alternative medicine (CAM) therapy usage and needs. You are being asked to take part in this short survey, which should take about 30 minutes to complete and at a later time 1 hour long interview will be completed as well. Your total expected time commitment to participate in this study is 2 hours.

Your participation in the study is completely voluntary and you may choose to stop participating at any time and for any reason. If you decide not to participate or to refuse to answer certain questions it will not change the health care and support you receive for your child with autism, nor your relationship with UBC either now or in the future.

Information supplied by you during the research will be kept confidential and your name will not appear in any report or publication of the research. All documents and recordings will be safely stored in a locked filing cabinet within a locked office at the University of British Columbia and only the researchers will have access to this information. The recordings will also be stored on a computer hard drive stored at UBC, which is password protected and accessible only to Ms. Tara Hodgson. Confidentiality will be provided to the fullest extent possible by law. After analysis of the findings, we will share our results through published articles, reports and presentations with other researchers, health care workers and service providers to deliver better care to families of children with autism.

If you have questions about the research in general or about your role in the study, please feel free to contact Ms. Tara Hodgson.
You may also contact Dr. Lynda Balneaves, who is supervising Ms. Hodgson’s thesis research at UBC School of Nursing.

If you have any concerns about your treatment or rights as a research subject, you may contact the Director of Research Services at the University of British Columbia.

By filling in this survey you are giving your consent to participate in the CAM therapy and Autism study conducted by Ms. Tara Hodgson and that you have understood the nature of this project and wish to participate. Written consent will be obtained prior to the commencement of the interview.
For this study, CAM is defined as a group of medical and health care systems, practices, and products that are not typically considered to be part of conventional medicine. These include whole medical systems, such as homeopathic and naturopathic medicine; mind-body therapies like prayer and meditation; natural product therapies that focus on vitamin, mineral, probiotics and herbal supplements; manipulative and body-based practices such as massage and chiropractic work, and energy medicine practices such as Reiki and therapeutic touch.

The researchers in this study in no way advocate the use of, or promote the efficacy of, any of the CAM therapies listed in this questionnaire. The CAM therapies listed are those reported being used in previous research.

1. What is your birth date (day/month/year)? _____/_____/_____

2. What is the birth date of your child (day/month/year)? _____/_____/_____

3. What is your gender?
   - Female
   - Male
   - Transgendered

4. What is your marital status?
   - Single
   - Married
   - Common-law
   - Divorced
   - Widowed

5. What is the highest level of education that you have achieved?
   - Less than high school
   - High school diploma
   - Some college/trade school
   - College/trade school diploma
   - Some university
   - Bachelor’s degree
   - Graduate degree

6. Please indicate your employment status:
   - Employed, full-time
Employed, part-time
Self-employed
Student
Retired
Unemployed
Other (please specify) ________________________________

7. What ethnic, cultural, or racial group do you most closely identify with? ________________________________

8. Because of the cost associated with treatments for autism symptoms can be expensive, income can be an important factor in making treatment decisions. What is your total household income?
   - Less than $10,000
   - $10,000 to $29,999
   - $30,000 to $49,999
   - $50,000 to $69,999
   - $70,000 to $99,999
   - $100,000 or more
   - Do not wish to disclose

9. When was your child diagnosed with autism (month/year)? _____/____

10. Have you used any complementary or alternative medicine (CAM) therapies for your child since they were diagnosed with autism? By CAM we are referring to a group of diverse medical and health care systems, practices, and products that are not generally considered to be part of conventional medicine. Complementary medicine refers to use of these practices in conjunction with conventional medicine, whereas alternative medicine refers to the use of these therapies in place of conventional medicine.
   - Yes
   - No (If NO, please skip to Question 12)

11. Below is a list of CAM therapies that some parents of children with autism have reported using as part of their child’s care. Please check all complementary and alternative medicine (CAM) therapies you have used for your child since they have been diagnosed with autism.
<table>
<thead>
<tr>
<th>CAM</th>
<th>Presently Using</th>
<th>No Longer Using</th>
<th>Considering Using</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Biologically-based therapies</strong></td>
<td></td>
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<tr>
<td>Aloe Vera</td>
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<tr>
<td>Antifungal treatments for yeast</td>
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<tr>
<td>Dimethylglycine (DMG)</td>
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<td>Efalex oil</td>
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<td>Docosahexaenoic acid (DHA) oil (Omega 3 fish oils)</td>
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<td>Flower of Sulphur</td>
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<tr>
<td>Magnesium</td>
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<tr>
<td>Probiotics</td>
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<tr>
<td>Magnesium &amp; B6</td>
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<td>Magnesium &amp; B12</td>
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<tr>
<td>Nutritional supplements</td>
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<td>Melatonin</td>
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<tr>
<td><strong>Diets</strong></td>
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<tr>
<td>Gluten free diet</td>
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<td>Casein free diet</td>
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<td>Sugar free diet</td>
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<td>Additive or preservative free diet</td>
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<td>Energy therapy</td>
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<td>No Longer Using</td>
<td>Considering Using</td>
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<td>CAM</td>
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<td>Reiki</td>
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<tr>
<td>Therapeutic Touch</td>
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<td><strong>Manipulative or body-based therapy</strong></td>
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<td>Chiropractic medicine</td>
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<td>Cranial sacral manipulation</td>
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<td>Deep-breathing exercises</td>
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<td>Massage</td>
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<td><strong>Mind-body therapy</strong></td>
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<td>Art therapy</td>
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<td>Guided imagery</td>
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<td>Hypnosis</td>
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<td>Meditation</td>
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<td>Music therapy</td>
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<tr>
<td>Homeopathic medicine</td>
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<td>Naturopathic medicine</td>
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<td>Traditional Chinese Medicine</td>
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<td>Ayurvedic Medicine</td>
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<td><strong>Other types of complementary therapies</strong></td>
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<td>Hypobaric oxygen chamber</td>
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<td>Chelation therapy</td>
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<td>Animal Therapy</td>
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<td>Other</td>
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12. Have you spoken to a health care provider about using CAM for your child with autism?
   □ Yes
   □ No

13. If yes, **Please check all** the health care providers you spoken to about using CAM for your child with autism:
   □ Behavioral therapist
   □ Dietitian
   □ Doctor/pediatrician
   □ Naturopath
   □ Nurse
   □ Pharmacist
   □ Social worker
   □ Tradition Chinese Medicine Practitioner
   □ Occupational Therapist
   □ Physiotherapist
   □ Other (please specify):
   ______________________________________________________
Appendix G
PARENTAL SELECTION OF COMPLEMENTARY AND ALTERNATIVE MEDICINE FOR AUTISTIC CHILDREN: CONSENT FORM

Principal Investigator: Dr. Lynda Balneaves, Associate Professor, Nursing, UBC

Co-investigators: Dr. Elizabeth Saewyc, Professor, Nursing
Dr. Pat Mirenda, Professor, Educational and Counselling Psychology and Special Education
Ms. Tara Hodgson, Graduate Student, Nursing

What is the purpose of this study?
The purpose of this study is to try and understand why parents choose to use complementary and alternative medicine (CAM) therapies for their children with autism. This study is being conducted as part of Ms. Tara Hodgson’s thesis research at the UBC School of Nursing.

What are you being asked to do?
You are being asked to take part in a short survey and a 1 hour long interview.

- A researcher will send you a short survey, via e-mail or mail, to fill out regarding your use of CAM therapies for your child; this should take about 30 minutes.
- A researcher will ask you questions about why you decided to use CAM therapies for your child.
- She will record your conversation. The recording will be transcribed.
- The interview will usually last no more than 1 hour.
- Your total expected time commitment to participate in this study is 2 hours.
- The interview will usually take place in a quiet location, such as your home, at a time that is convenient for you.

What are the risks of taking part in this research?
- We do not foresee any risks or discomfort from your participation in the research, however, the interview process may trigger some feelings that are sensitive for you. If this happens, you may choose to stop the interview. You can also receive a list of resources that can provide you and your family with support related to any negative feeling you may experience following the interview.

- The researcher is legally obligated to report any suspected child abuse and this duty overrides any researcher/ participant confidentiality obligation; therefore any disclosure of privileged information regarding the treatment of your child that could be considered abusive may require legal action on behalf of the researcher.
Voluntary Participation:
Your participation in the study is completely voluntary and you may choose to stop participating at any time. If you decide not to volunteer it will not change the health care and support you receive for your child with autism, nor your relationship with UBC either now or in the future.

Withdrawal from the Study:
You can choose to stop participating in the study any time and for any reason, if you so decide. Your decision to stop participating, or to refuse to answer certain questions, will not change the health care and support you receive for your child with autism, nor your relationship with UBC either now, or in the future.

Confidentiality:
Information supplied by you during the research will be kept confidential and your name will not appear in any report or publication of the research. All documents and recordings will be safely stored in a locked filing cabinet within a locked office at the University of British Columbia and only the researchers will have access to this information. The recordings will also be stored on a computer hard drive stored at UBC, which is password protected and accessible only to Ms. Tara Hodgson. Confidentiality will be provided to the fullest extent possible by law.

Who else might see my information?
Only members of the research team listed above will have access to the information. This includes the principal investigator and the co-investigators.

Benefits of the Research and Benefits to You:
After analysis of the findings, we will share our results through published articles, reports and presentations with other researchers, health care workers and service providers to deliver better care to families of children with autism.

Questions about the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Ms. Tara Hodgson.
You may also contact Dr. Lynda Balneaves, who is supervising Ms. Hodgson’s thesis research at UBC School of Nursing.

If you have any concerns about your treatment or rights as a research subject, you may contact the Director of Research Services at the University of British Columbia.
Consent
I ___________________ consent to participate in the CAM therapy and Autism study conducted by Ms. Tara Hodgson. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

I have received a copy of this consent form for my own records.

I consent to participate in this study.

Printed Name ______________________________________

Signature __________________________________________
Date ______________________________________________
Participant

Witness: Principal Investigator

Printed Name ______________________________________

Signature __________________________________________
Date ______________________________________________

Appendix H
Interview Questions

The questions that will be posed to study participants initially are:

1. Can you tell me briefly about what it was like for you when you initially received the diagnosis of autism for your child?
   a. Probes: When do you believe your child’s autism began? What do you believe caused your child’s autism?

2. How did you think CAM therapies would help your child, if at all?

3. Once you received the diagnosis of autism for your child, what were the steps you took towards selecting a treatment for your child?

4. Where did you look for information about treatment options for autism?

5. What factors influenced your decision to try a CAM therapy(s)?

6. Who influenced your decision to try a CAM therapy?

7. Why did you choose (a particular therapy)?

8. How did you decide what CAM therapies not to use?

9. What kind of outcome were you hoping to see when you tried CAM therapies?

10. Do you think that CAM therapies helped your child? If yes, how?

11. How was the way you made the decision to use a CAM therapy different than how you made health care choices for your child prior to their diagnosis?

12. Were there any CAM therapies that you decided not to use? If so, why? What influenced your decision not to use that therapy?

13. What type of information would have been helpful to you and your family in making a decision about CAM therapies?
Appendix I

Participant Support

Living Through Loss Counselling Society of BC:

LTLC provides professional grief counseling to adults and children who have experienced any type of loss. We offer a confidential and supportive environment in which to discuss your concerns. #206-1651 Commercial Dr,
Vancouver BC V5L 3Y3
(corner of 1st and Commercial)
Phone: 604.873.5013
Fax: 604.873.5002
Email: ltlc@shaw.ca

Parent’s Support Services Society of British Columbia:
Toll Free: 1.877.345.9PSS (9777)
Phone: 604.669.1616
Fax: 604.669.1636
E-mail: office@parentsupportbc.ca

Regional Program Offices

Metro Vancouver/Coastal/Fraser Valley/Interior:
204 - 5623 Imperial St.
Burnaby, BC V5J 1G1
Toll Free: 1.877.345.9PSS(9777)
Phone: 604.669.1616
Fax: 604.669.1636
E-mail: office@parentsupportbc.ca

Victoria Office:
2541 Empire St.
Victoria, BC V8T 3M3
Toll Free: 1.877.345.9PSS(9777)
Phone: 250.384.8042
Fax: 250.384.8043
E-mail: parent-support@shaw.ca

Central Island Office:
P.O. Box 86
NanOOSE Bay, BC V9P 9J9
Toll-Free: 1.877.345.9PSS(9777)
Phone: 250.468.9658
Fax: 250.468.9668
Email: parent@telus.net

Prince George Office:
P.O.Box 21106
Spruceland R.P.O. 693 West Central Street
Prince George, BC V2M 2A5
Toll-free: 1.877.345.9PSS (9777)
Phone: 250.962.0600
Email: parentnorth@shaw.ca
Safe Kids BC Helpline for Children: Available to any child or youth, parent or community member who is being hurt, suspects a child of being hurt or is afraid they will abuse a child. Call is confidential and your call will be answered by a trained child protection worker.

Phone 310-1234 (no area code needed).
After Hours Line: For emergencies outside office hours, call the Helpline for Children at 310-1234. Or, call:
  - Vancouver, North Shore Richmond, call (604) 660-4927
Lower Mainland, Burnaby, Delta, Maple Ridge, Langley, call (604) 660-8180
For the rest of the province, call toll-free 1-800-663-9122

Spousal Abuse/Family Violence Transition Houses:
Safe housing for women and children experiencing domestic abuse and relationship violence
Vancouver: 604-872-7774 (24 hours/day)
Burnaby: 604-298-3454 (24 hours/day)
Richmond: 604-270-4911 (24 hours/day)
North Vancouver: 604-987-3374 (24 hours/day)

Our Lady of Good Counsel Society - Domestic Abuse Services:
Provision of an abuse helpline, individual support, safe housing when available, access to spiritual, legal, financial and psychological resources as well as education for people about domestic abuse and relationship violence.

2881 Main Street, Vancouver, BC
Phone: (604) 708-8402 Fax: (604) 708-8403
E-mail: das_olgcs@telus.net
http://www.domesticabuseservices.ca/home.htm