A FEMINIST ANALYSIS OF MOTHERHOOD:
EXPERIENCES MOTHERS OF A CHILD WITH AUTISM
HAVE WITH THEIR SUPPORT SYSTEM

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ABSTRACT

Some feminist theorists have commented that feminism has succeeded only up to a point – and that point is motherhood. Motherhood, these theorists say, remains one of society’s greatest untold stories. This study examines the subjective experiences of one small but important segment of mothers – mothers of a child with autism. The current literature on this topic is mainly focused on the autistic child and only recently has the impact on family members been explored. What relatively little literature exists is focused on “parents”, not mothers, thus hiding the gendered nature of care, and is mainly quantitative, anecdotal, and focused on the impact of caring for children with generalized “special needs” – not on children with autism. To date, there has not been a comprehensive gender-sensitive qualitative study about the experiences of mothers caring for a child with autism. The goal of this study is to better understand the personal experiences of these mothers in terms of their interaction and relationship with their support system.

Information was gathered through the use of semi-structured interviews with eight mothers. Analysis of their transcripts revealed three themes. Mothers experienced and felt: (1) ignored; (2) abandoned; and (3) like burdened “Supermoms.”
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CHAPTER 1  SETTING THE STAGE

Introduction

One of every 1,000 children in North America is born with autism or an autism spectrum disorder (Waltz, 1999, p. 2). Waltz defines autism as “a neurological disorder that features marked impairment in social interaction and communication, as well as restricted, repetitive patterns of behaviours, activities, or interests. It is often, but not always, accompanied by some degree of mental retardation (1999, p. 22).” The degree of impairment depends significantly on the degree of mental retardation (Waltz, 1999, p. 24).

Autism spectrum diagnoses include Asperger’s Syndrome and autistic tendencies and are themselves included under an umbrella diagnostic label known as Pervasive Developmental Disorder (PDD) (Waltz, 1999, p. 2). Autistic behaviours range from difficulties handling transitions, maintaining poor eye contact, and having poor social skills, to being aggressive to others or self and having extreme temper tantrums. However, each child or adult with autism has their own unique pattern of symptoms and behaviours (Waltz, 1999, p. 3). Children with autism are also affected with several other neurological disorders more frequently than in the general population. These include: affective disorders, particularly depression, Attention Deficit Disorder, phobias and other anxiety disorders, obsessive-compulsive disorders, and Tourette syndrome (Waltz, 1999, p. 13). The autistic symptoms may worsen if the child also has a seizure disorder, particularly one that is not well controlled (Waltz, 1999, p. 20).

This qualitative research study takes a feminist perspective to explore one aspect of
the experiences of mothers a child with autism: their experiences with their support system. There is an overwhelming amount of literature on autism, although the vast majority of it is focused on the autistic child, covering such topics as treatment, psychological development, diagnostic issues, and so on. There has only recently been a focus on the experiences of “family members” in families with a child with special needs and/or autism (Seligman & Darling, 1997, pp. 1-2). The literature on “parenting” a child with special needs and/or autism hides the gendered nature of care (Hooyman & Gonyea, 1995, p. 122; Read, 2000, p. 52; & Traustadottir, 1991, p. 226). The vast majority of this “parenting” literature is quantitative and lacks any insight into the subjective experiences of parents caring for any child, let alone specifically a child with special needs and/or autism (Lee, G., 1992 & Parks, H., & Pilisuk, 1991 as cited in Hooyman & Gonyea, 1995, p. 130 & p. 151; & Woolley, 2000, p. 48). What information exists about parents’ experiences of caring for a child with special needs and/or autism is almost entirely anecdotal (Seligman & Darling, 1997, p. 90). This anecdotal literature, although very powerful and helpful, makes no attempt to more thoroughly understand this phenomenon through systematic gathering, analyzing, and interpreting the experiences of parents. What few formal qualitative studies exist lack a feminist analysis that places the experiences of mothers within the well-documented context of the patriarchal institution of motherhood. These few qualitative research studies also focus on the care of children with various special needs and not on autism specifically. So far, the voices of mothers of a child with autism, from a qualitative and feminist perspective, have yet to be heard.

This lack of information about the experiences of mothers caring for a child with
special needs and/or autism reflects the similarly glaring gap in our knowledge about the experiences of mothers in general. Despite the institution of motherhood holding such an oppressive grip on mothers, their story remains largely untold (Brown, 1994, p. 8 & p. 151; Fox, 1997, p. 143; Gerson, Alpert, & Richardson, 1990, p. 16; Hirsch, 1990, p. 178; Miller-McLemore, 1999, p. 287; Lerner, 1998, p. xiv & p. 47; O’ Barr, Pope, & Wyer, 1990, pp. 3-4; & Rossiter, 1988, p. 177). In fact, Maushart writes: “What human beings need to know about mothering is perhaps the greatest story never written (2000, p.246).” Forna (1998) writes: “Motherhood is the largest single remaining obstacle to women achieving equality in contemporary, post-modern society. The problem is not children, having children, or the love and care of children, but the framing of Motherhood and the endurance of the myths that surround it (p. 260).”

Not only have male researchers ignored motherhood, but so too have feminist scholars (DiQuinzio, 1999, pp.xi-xii; Maushart, 2000, p. 241; & Peters, 1997, p. 48) – although others would argue that what is known about the institution of motherhood is largely due to feminist scholars (O’ Barr, Pope, & Wyer, 1990, p. 1). The first wave of feminists focused on equity in education and employment. They thought that emancipation in those areas would naturally lead to emancipation for women in the oppressive conditions of marriage and motherhood, but it did not (Maushart, 2000, p. 178). In fact, feminism has only succeeded up to a point – and that point is motherhood (Luxton, 1997, p. 8; & Maushart, 2000, p. 243). Motherhood, not gender, remains the great “disequilibrator” between women and the oppressive force between men and women (Maushart, 2000, p. 178). Forna writes:
Rich apart, popular feminism did little to address the issue of motherhood directly. In its vast literature, precious little has been devoted to the issue of motherhood, which was seen as part and parcel of an overall package of oppression.... The omission left a glaring gap, and in time the institution of motherhood has become the neglected vulnerable spot of the Western women’s movement (1998, p. 71).

Another specific gap in our knowledge of motherhood in general is the differences in mothers’ experiences. Glenn (1999) says what is needed is a focus on the variation of mothers’ experiences rather than searching for some universal experience and to shift what has been on the margins to the center (p. 5). She goes onto say that: “[the] social constructionist view implies that searching for universals that characterize mothers and mothering is probably fruitless (p. 25).” Mothers caring for a child with autism is clearly one of those unique but neglected areas on the margins of mothers’ experiences since there has yet to be a qualitative research study from a feminist perspective about any aspect of their experiences.

There are many negative consequences for mothers as a result of this gap in our knowledge about their experiences. As a result of this lack of openness about motherhood, most women experience motherhood as being much more difficult than expected (Brown et al, 1994, p. 144). Each woman quietly thinks to herself that she is alone in feeling overwhelmed, frustrated, and angry. She maintains her silence thinking that it is unnatural to feel this way and knowing that if she expressed these feelings people would react with disapproval and rejection (Brown et al, 1994, p. 161; & Forna, 1998, p. 23). Mothers also often silence themselves trying to live up to the impossible standards of motherhood (Brown et al, 1994, p. 162) and begin to believe that there must be something the matter

Hiding the gendered nature of care giving leads to a neglect of policies and programs for mothers (Evans and Wekerle, 1997, pp.19-23; Forna, 1998, p. 228; & Traustadottir, 1991, p.212). This lack of knowledge of mothers’ experiences also means that when governments want to move forward in this area and develop some much needed policy and services, there is no research data available (Peters, 1997, p. 50).

**Conceptual Context**

The purpose of this study is to begin filling in one aspect of these gaps in our knowledge: to better understand the experiences mothers of a child with autism have with their support system, and in so doing to begin addressing some of the resulting negative consequences mentioned above. Research such as this study will bring heightened attention to the needs of this population. Such attention will make it more difficult for policy makers to continue ignoring the needs of mothers as primary caregivers in general and of mothers of children with autism in particular. The findings from this study may assist in developing new studies and projects and in sharpening the focus of future analysis of such mothers’ experiences (Peters, 1997, p. 56). This study will begin to end the silence of at least some mothers of a child with autism and give them a voice to share their issues and concerns. This study may also help to prepare new mothers for what lies ahead, making them feel less alone and incompetent in making sense of an overwhelming experience and to feel less fettered by non-productive guilt, anxiety, and self-blame (Lerner, 1998, p. xv). By sharing the experiences of other mothers in similar situations, mothers reading this study, such as
the mothers who participated in this study, may feel "affirmed," "supported," "less alone," and "strengthened" in dealing with their own issues (Marsh, 1995, p. ix). Feminist studies like this one about the experiences of mothers will begin to give mothers a framework to better understand the patriarchal context that moulds and constrains their experiences. Such an expansion of the current knowledge of mothers’ experiences will enrich our understanding of the variation in mothers’ experiences – thereby begin to take the experience of mothers of autism off the margins and onto centre stage.

This is not a study into the experiences mothers have of the actual caring for a child with autism. Instead, it is a beginning exploratory study that seeks to describe the experiences mothers of a child with autism have with their support system. The overall design and analysis was guided by the feminist literature on motherhood. As such, one of the key assumptions of this study is that many mothers are unfairly burdened with the bulk of childcare and household responsibilities and as such they experience considerable hardship and burdens trying to meet the impossible expectations patriarchal society has of mothers.

Reinharz has identified ten themes in feminist research (1992, pp. 240-269). One of these themes involves the researcher situating him/herself and explaining why a particular topic was chosen. I chose to take a feminist approach to this study for three reasons. The first reason relates to my findings after doing an extensive literature review on feminism’s critique of motherhood and of the experiences of mothers caring for a child with autism. The voice and stories of mothers in general were still largely untold, despite the harsh reality of these mothers’ experiences. I decided to focus specifically on one area of the
experiences of mothers of a child with autism in order to begin addressing this gap in our knowledge and to acknowledge this unfair reality. Secondly, focusing on the experiences of mothers, as opposed to the more common approach of focusing on the experience of “parents”, seemed to fit much better with my experience as a social worker for families with a child with special needs. In the thirteen years that I have worked as a social worker for the British Columbia Ministry for Children and Family Development, Community Living Services, I have consistently found, in the vast majority of situations, that most fathers play only a peripheral role in the care of their child with special needs while the mothers play the central role as primary caregiver. Taking a feminist perspective, therefore, was the most truthful account of these mothers’ experiences. As Rossiter states: “If research reflects an understanding of our culture, then it is clear that such understanding should articulate women’s experience within patriarchy (1988, p.16).” Lastly, as a relatively new father, there is still much more that I need to learn and practice about becoming a more equal, emotional, supportive partner; and a more proactive, nurturing, and involved father. Taking a feminist approach for this study allowed me a great opportunity to take this personal journey and to explore the very enlightening, powerful, and empowering feminist ideas about self and parenting.

I will now outline the remaining sections of chapter one. In section two I will take a step back and look at the economic, political, and social context that mothers face, focusing mainly on the current crisis in service delivery and the institution of motherhood. In section three I will discuss the hardships mothers experience in the areas of housework and childcare. In section four I will focus on “supermoms”, mothers who are employed
outside of the home and who still maintain the vast majority of housework and child care responsibilities. In section five I will discuss issues that are unique to mothers of a child with autism. In the sixth and final section I will review and critique several key studies that are relevant to the experiences of mothers of a child with autism.

**The Social, Political, and Economic Context of Motherhood**

**Cutbacks in Service Delivery and the Resulting Impact on Mothers**


Families caring for a child with special needs have been enduring very long waitlists for services for some time, for such services as respite, behavioural consultation, life skills workers, and day programs (Seligman & Darling, 1997, p. 83). Yet, Seligman and Darling go on to argue, it is the provision of these formal support services for parents of a child with special needs that more than anything else (including parental competence or level of acceptance), determines how well a family adapts to their situation (Seligman & Darling, 1997, p. 79).
Governments simply assume that women will fill the void left by the cutbacks in formal support services (Evans & Wekerle, 1997, p.7; & Luxton, 1997, pp. 21-24; & Luxton and Reiter, 1997, p. 215). Often these cutbacks mean that these mothers have to reduce their hours of outside work or quit work altogether in order to fill this void, thereby wreaking harsh short-term and long-term financial costs in terms of less income and lower pension benefits (Evans, 1998, p.47; & Forna, 1998, p.226) and limiting their opportunities for self-development (Aronson, 1998, p. 116).

The Institution of Motherhood

A patriarchal ideology defines gender roles in such a way that women are primarily assigned the inferior role of caring for others while men are primarily assigned the superior role of working and providing for others. A woman’s world is her family while a man’s world is his work (Gordon, 1990, p.11, & Evans, 1998, p. 48). Women and men are understood in Western cultures to be two very different types of people, with very clear and opposite attributes, and with men’s attributes considered superior to those of women. With women’s attributes, such as their caring role, being considered inferior to men’s attributes, women’s caring and housework are consequently devalued (Aronson, 1998, p. 142).

Such gender differences are engrained in us at a very early age. Numerous studies have shown that from a very young age girls are socialized and in fact “policing” into a caring role where they learn to negate their needs for the needs of others (Fox, 1997, p.144; Murphy, 1990, p. 223; O’Barr, Pope, & Wyer, 1990, p. 11; & Reitsma-Street, 1998). Referring to a number of studies, including one of Canadian high school girls, Fox states that the anticipation of mothering, more than anything else, seems to distinguish girls from boys (1997, p. 144). In fact, girls are taught at a very young age that females – not boys – are care providers (Ferguson, 1998, p. 207; & Rossiter, 1988, p. 117), and that it is very
important to look nice and to be nice and to make boy-friends the objects of caring. (Baines, 1998, p. 91-92; & Reitsma-Street, 1998, p. 92). Learning to make boys their major object of caring is a phenomenon for girls across all races (Reitsma-Street, 1998, p. 94).

Once a girl becomes a woman and later a mother, the patriarchal institution of motherhood expects nothing less of her than total sacrifice. The good mother is the all-sacrificing mother (Cooper, 1999, p. 270; DiQuinzio, 1999, p. xiii; Fellman, 1990, p. 228; Forna, 1998, p. 3; & Fox, 1997, p. 155). Forna writes: “The motherhood myth is the myth of the ‘Perfect Mother.’ She must be completely devoted not just to her children, but also to her role. She must be the mother who understands her children, who is all-loving and, even more importantly, all-giving. She must be capable of enormous sacrifice (1998, p.3).”

The force that drives mothers to be so self-sacrificing is the ever-powerful and ever-present emotion of guilt (Forna, 1998, p. 12; Lerner, 1998, p. 75; & Rossiter, 1988, p. 137). Forna writes: “Working alongside the idealized depiction of motherhood is the second tool of enforcement: guilt. Guilt has become so strongly associated with motherhood that it is often considered to be a natural emotion (1998, p. 12).” Guilt forces mothers to question their own behaviour rather than their oppressive circumstances (Lerner, 1998, p. 75).

Guilt can be particularly painful and powerful for mothers of a child with special needs. Professionals sometimes expect mothers of special needs children to follow-through on complex, time-consuming, and unrealistic interventions; and this can generate considerable guilt in mothers if they are not able to live up to these impossible standards (Kittay, 1999, p. 22).

Once mothers are assigned the responsibility of caring work, this work then becomes undervalued, invisible, unacknowledged, ignored, and/or even treated with contempt (Baines, Evans, Neysmith, 1998, p.4; Brown et al, 1994, p. 161 & 202; Fellman, 1990, p. 229; Ferguson, 1998, p. 197-200; Fineman, 1999, p. 149; Fox, 1997, p. 153; Gerson, Alpert, & Richardson, 1990, p. 32; Nedelsky, 1999, p. 321; & Rossiter, 1988, p. 97 & p. 277); disempowered and disregarded (O’Barr, Pope, & Wyer, 1990, p. 2); or only noticed when it does not get done (Brown et al, 1994, p.202). This is the same experience for mothers of disabled children (Read, 2000, p. 56). Part of this emotional toll on mothers is due to the fact that this very exhausting but incredibly important role goes unacknowledged by society in general and by partners in particular, and this really “drags mothers down” (Brown et al, 1994; Maushart, 2000, p. 121; & Nedelsky, 1999, p. 320).” Mothers are on the one hand ignored and considered irrelevant, yet on the other hand are
blamed for all failures. Rossiter writes: “We can clearly see the double bind which applies to mothers: mothers are invisible and inexpert; but, though they are powerless, they are at the same time responsible for all failures (1988, p. 175).”

In summary, the patriarchal institution of motherhood assigns the responsibility of caring first to girls, then later to women and mothers. Guilt is a pervasive tool of patriarchy used to enforce the self-sacrificing standard of the “Perfect and All-Giving Mother.” Having assumed that women are natural mothers and assigning caring responsibilities to them, their work is then often devalued, unacknowledged, ignored, or only noticed when it does not get done. It is to the heart of this work – housework and childcare – that we now turn our attention.

**Housework and Childcare**

While most men and women report that they think household chores should be split 50/50, the reality is that today women still do the vast majority of household chores (Gordon, 1990, p. 15; & Wooley, 2000, p. 29). Men do only a “measly 2 hours more of housework” – up to a total of 13 hours per week – when compared to the 11 hours per week they did three decades ago (Maushart, 2000, p.185). Only one-fifth of fathers are “fully involved” in sharing housework responsibilities (Maushart, 2000, p.186). Near the other end of the continuum, only about one-fifth of fathers even “help out” with household chores (Gordon, 1990).

Women tend to do the daily urgent tasks, like preparing meals and dressing the kids in the morning, that fix them into a routine (Maushart, 2000, p. 186; & Wooley, 2000,
Men tend to do household tasks that, while more physically demanding, are also more intermittent and less urgent (Fox, 1997, p. 144; & Luxton & Reiter, 1997, p. 205). As Brown et al state: “One of the things that domestic labour and child care have in common is their never-ending nature: the task is literally never done (1994, p. 205).” Mitchell (1996), as reported in Maushart (2000, p. 186), concluded that, out of the five household chores examined, only one was routinely done by men – household repairs. Barnett (1997), as reported in Maushart, compared the effects of men’s relatively low-pressure, high-control household tasks with those of women’s high-pressure, low-control household tasks. The latter tasks were found to be significantly related to anxiety and depression.

This inequitable division of labour regarding household chores is clearly one of the biggest issues of marital discord in the first few years of marriage (Fox, 1997, p. 151). Women often feel ultimately responsible for overall housework, while men either think they are doing more housework than their partners say they are (Wooley, 2000, p. 33) or expect to be praised for their “helping out” with what they see as women’s work (Brown et al, 1994, p. 163; & Gordon, 1990, p. 132). Men justify such inequity in household chores by comparing themselves to what other men do for their partners, while women, quite rightly, compare what their partners do with what they themselves do (Gordon, 1990, p. 132). In fact, women need to even ask “permission” for the privilege of doing their household chores in peace and without interruptions, yet when men need to do “big jobs” around the house these conditions are deemed necessary (Maushart, 2000, p. 228).

Just as men consider themselves to be “helping out” with women’s work when they occasionally do some household chores, so too do they consider themselves to be helping
out when they “baby-sit” their own children. (Brown et al, 1994, p. 163 & 211; Forna, 1998, p. 226; & Maushart, 2000, p. 225). In fact, mothers and fathers are forced into separate worlds based on traditional stereotypical roles (Brown et al, 1994, p. 168; Cowan and Cowan, 1992, p.112; Forna, 2000, p. 220; Fox, 1997, pp. 143-145; Lerner, 1998, p. 33, & p. 54; Oakley, 1990, p. 76; & Peters, 1997, p.10). Such role changes lead to substantial change in women’s lives and identities and only marginal change in men’s lives and identities (Brown et al, 1994, pp. 162-166). Maushart writes: “For men, family life – which translates almost universally into full-time work and peripheral parenting – still works. For women, increasingly, it does not...Instead of ‘having it all’ we find that we are ‘doing it all’ (2000).” A study by Brown et al showed that fathers were much less likely than mothers to have given up the leisure-time pursuits they enjoyed prior to parenthood. (1994, p. 225).

This gender-based division of labour is replicated with families having a child with special needs (Cook, J., 1988, p. 43; & Marsh, 1995, pp. 103-124). Hooymann and Gonyea (1995, p.120) write: “One of the most consistent findings in family research is that, across the family life cycle, the vast majority of carers for relatives with chronic disabilities are women.” Traustadottir writes: “A review of gender roles and responsibilities within families of children with disabilities reveals a division of labour that follows a very traditional pattern where the father’s primary responsibilities are related to the world outside of the family, and the mother’s responsibilities are within the family (1991, p. 221).” Forcing women into this all-consuming role for which they have total responsibility has harsh consequences for mothers.
**Burdens of Motherhood**

New mothers experience a variety of negative emotions in the first few years. These emotions include feeling: intimidated, terrified, frustrated, depressed, anxious (Cooey, 1999, p. 238; Fox, 1997, p. 153 & p. 144; & Lerner, 1998, p. 45); isolated (Fox, 1997, p. 153); enraged (Cooey, 1999, p. 238); guilty (Cooey, 1999, p. 238); constrained and “trapped” (Fox, 1997, p. 152); physically and emotionally drained (Brown et al, 1994, p. 139; & Rossiter, 1988, p. 71); ambivalent about motherhood (Brown et al, 1994, p. 170); and struggling with “sheer emotional survival” (Rossiter, 1988, p. 171). Some have gone so far as to say that marriage and children are a “health hazard” for women (Bernard, J. as cited in Gerson, Alpert, & Richardson, 1990, p. 30). Brown et al write: “Not only does it seem unjust that ‘women’s work is (still) never done’, but it is evident that the burdens borne by women in this uneven distribution of work, especially when it is accompanied by a lack of acknowledgment of their work, and little emotional support from their partners, can have serious consequences for women’s emotional well-being (1994, p. 226).”

Mothers of a child with a disability often “arrange their whole lives around the caring work and the child” because of the constant and severe needs of many of these children. Some of these needs require mothers to “constantly supervise” their child, to be up most of the night with their child with a sleeping disorder, “to constantly fight for services,” and to coordinate many different professionals on their child’s team (Traustadottir, 1991, p. 221).

One of the ways that mothers cope with this overwhelming amount of never-ending responsibility is to negate their own needs so that they can meet the needs of others.
Maternal self-sacrifice is both an ideal of motherhood and a coping means of mothers trying to live up to impossible standards of motherhood (Brown et al, 1994, p. 162; & Rossiter, 1988, pp. 57-61). Brown et al report that the majority of new mothers have no time for activities involving self-interest, no social life, are less confident since becoming a mother, and in need of a break (1994, p. 165). One of the key findings from the Traustadottir study was that the family only found the child’s disability as restricting if it restricted the family’s activities – not the mother’s activities (1991, p. 223).

It should come as no surprise that forcing mothers to continually negate their own needs in order to meet the needs of others, can lead to depression. Yet the traditional medical post-partum depression literature is almost completely lacking in any acknowledgment of this connection between mothers’ neglect of their needs and severe depression (Brown et al, 1994, p. 173; & O’Barr, Pope, & Wyer, 1990, p. 5), or has only recently begun to explore the various social/emotional causes of depression (Gerson, Alpert, & Richardson, 1990, p. 25; & Oakley, 1990, p. 70), such as the draining effects of sleep deprivation, exhaustion, work overload, social isolation, and the loss of an autonomous self (Maushart, 2000, p. 123; Lerner, 1998, pp. 54-57; & Rossiter, 1988, p. 244). The cause for such mother’s depression is not the baby itself, but rather is simply a mother’s effort to resist and rebel against overwhelming expectations of mothering in general (Maushart, 2000, p. 121).

While there are many burdens associated with being a mother, there are also unbelievable joys and rewards involved in this most important of all possible jobs (Brown et al, 1994, p. 206; DiQuinzio, 1999, p. 209; & Gordon, 1990, p. 49; & Seligman & Darling,
The majority of the current literature focuses on the negative aspects of caregiving and thus neglects the gratifying and fulfilling aspects of such caregiving (Gerson, Alpert, & Richardson, 1990, p. 34). Hooyman and Gonyea state that a “more complex view of caring is needed, one that recognizes that taking on the caregiving role has both positive and negative implications for an individual’s life (1995, p. 138).” DiQuinzio reviews and critiques a number of feminist works on mothering and highlights two in particular that reveal the ambivalence many mothers feel about the contradictory hardships and joys of mothering. She writes: “Rich’s and Collin’s account of mothering recognize the extent to which women’s experiences of mothering include suffering, sorrow, frustration, restriction, fear, doubt, sacrifice, anger, failure, and violence, as well as joy, love, satisfaction, and accomplishment (1999, p. 209).”

As all-consuming as mothering can be, many mothers also have a life outside of mothering in various jobs and professions. The overlap between these two lives also needs to be examined.

**Employed Mothers**

“Men work from sun to sun, but a women’s work is never done (Maushart, 2000, p. 205).”

Although this study is concerned primarily with the experiences of “mothers” of a child with autism, I will spend some time focusing on the overlap these mothers experience as “workers” since the literature often tends to ignore these important overlaps (Maroney, 1997, p. 38).

In many Western societies two incomes are often no longer a luxury, but rather an
economic necessity (Brown et al, 1994, p. 137; & Wooley, 2000, p. 31). In 1995 57 % of all women (compared with 73 per cent of all men) were in the formal labour force in Canada (Luxton & Reiter, 1997, p. 201). For Canadian women between the ages of 25-44 the number of women employed jumps to 70.0% - up from 49.9 % for the same group in 1976 (1994 Statistics Canada as cited in Wooley, 2000, p. 30). For immigrant women in Canada the rates were comparable, although only 40 per cent of First Nations women worked in 1995 (Luxton & Reiter, 1997, p. 202). Sixty-four percent of married mothers and forty-seven percent of single mothers of preschool children worked in 1995 (Powell, 1997, p.11 as cited in Ferguson, 1998, p. 198).

The problem is that in addition to working full-time outside of the home, they are still burdened with nearly all of the household chores and child care responsibilities – a full-time job in itself (Ferguson, 1998, p. 198; Forna, 1998, p. 226; & Luxton & Reiter, 1997, p. 198 & 205). This is particularly true in Canada with seventy-three per cent of full-time employed mothers saying that they had sole responsibility for household health, care of the sick, disabled, and/or the elderly (Luxton & Reiter, 1997, p. 206). Seventy-eight per cent of employed women had sole responsibility for meal preparation, and seventy-seven per cent for cleaning and laundry (Luxton & Reiter, 1997, p. 206). Fathers do not increase their amount of household and childcare responsibilities when their partners are also working full-time outside of the home (Shelton, 1994). For South Asian women living in Canada, working outside the home in no way reduces their total obligation for all household and childcare responsibilities (George, 1998, p. 76). In fact, not uncommonly South Asian women are the sole breadwinners in the family, and yet they still retain all household and
child care responsibilities (Gill, 1995, as cited in, George, 1998, p. 77). When mothers of a child with a disability try to combine a career with being primary caregiver they face "an extraordinary amount of work," neglect their own needs, such as their need for sleep, are forced to become "expert managers", or come under tremendous pressure to quit work and remain at home (Traustadottir, 1991, pp. 221-225).

There are extreme emotional, psychological, and physical consequences for working mothers who try to balance these work and home responsibilities. These burdens include being chronically tired, irritable, and suffering from maternal guilt (Gordon, 1990, p.34). The only way that women can even try to meet all of their family's many needs, wants, and demands is by adopting a pattern of "self-neglect" (Lerner, 1998, p. 46; Maushart, 2000, p. 132, & Traustadottir, 1991, p. 211). Maushart states that women sacrifice their own sleep, food/diet, and time for exercising so that they can try to find the time to meet their family's needs (2000, p. 132). Maushart writes:

Mothers succeed in meeting family needs to the extent that their own needs are denied, disallowed, or indefinitely postponed. In this way, the functioning of contemporary family life is increasingly predicated on the functioning, indeed the quite literal dismembering, of women's lives. And if it seems an outrageous overstatement to say so, this is only because we take such sacrifice for granted. More often than any of us is comfortable admitting, mothers earn the right to work for pay by foregoing not only leisure, friendships, and community involvements but even basic, physical needs – especially sleep...I have no doubt that sleep deprivation is the greatest single contributing factor to women's precarious mental health during the active years of early mothering (Maushart, 2000, p. 206).

Mothers go to work for a break, while fathers go home for a break (Horschild, 1991). Lerner writes that women are slowly "discovering men's secret: that 'there's no place like work' to escape the pressures of home (1998, p.64)." If women decrease the amount of work they do outside of the home, then they inevitably end up increasing the
amount of domestic work they do. If men decrease their work outside the home, then this often translates into increased leisure time (Maushart, 2000, p.202). That is why it is a myth to believe that overworked mothers should simply work part-time to cope with this high level of stress. If mothers reduced their full-time work to just part-time, they would simply fill all of these extra hours with equally, if not more demanding, childcare and household work.

Some may ask why would women continue with such an unjust and terribly burdensome situation. For many different reasons, mothers end up “doing it all” at home, even if they are working outside of the home. Many women feel guilty about working for their self-interest and think that working is a privilege, not a right, so they repent with hard domestic labour (Hoschild, 1997, & Maushart, 2000, p. 180). Many are simply far too busy and exhausted to question their grossly unfair circumstances; or if they do, they realize it would require much more work than it is worth to “endlessly renegotiate the division of household labour with an unwilling partner”(Maushart, 2000, p.200). Some feminist scholars argue that many women will simply not let men do their fair share of household and childcare responsibilities. They state that such mothers are vigilant “gatekeepers” of the right to be primary caregivers and boss of certain childcare routines and activities and various household chores (Forna, 1998, p. 262; & Maushart, 2000, p. 223). There is often a power imbalance in a family’s home, with fathers having authority and most of the power. Often this leaves the mother with little negotiating power in getting her partner to equally participate in the household chores and childcare. The surest way to increase a women’s psychological and moral independence is for her to have an independent income (Crosby,
1991, p. 118). As reported in Crosby (1991, pp.168-169), studies have shown that housewives win one-quarter of domestic arguments, while employed mothers win one-half of such arguments. This same study showed that employed mothers have more decision-making power. In fact, the higher the women’s income, the greater her decision-making power in the family. These are only some of the many causes why mothers routinely endure very difficult and grossly inequitable circumstances.

**Issues Unique to Mothers of a Child with Special Needs**

While there are a great many mothering activities shared between mothers in general and mothers of disabled children, one of which is having to live their lives within the patriarchal institution of motherhood, there are also distinct differences (Read, 2000, pp. 25-26).

Mothers of a child with special needs or autism endure much more stress and for a much longer amount of time than do most mothers in general (Kittay, 1999, p. 11; Marsh, 1995, p. x; Read, 2000, p. 54; & Seligman & Darling, 1997, p. 96). Mothers caring for a child with special needs are often consumed by the intensity and permanency of the caregiving work – while mothers of “typical” children tend to mainly experience this intensity only while their children are very young (Kittay, 1999, p. 11 & p. 17; & Read, 2000, p. 21, p. 26 & p.54). Other studies have found that parents of a child with special needs whose main issues are behavioural (e.g. autism) face considerably more stress than do parents of a child with special needs whose main issues are physical in nature (e.g. spina bifida, cerebral palsy etc) (Seligman & Darling, 1997, p. 107; & Konstantareas, 1991). The
parents of a child with autism in particular face great challenges in treating the condition and/or “tolerating” the constant behavioural issues (Seligman & Darling, 1997, p. 111).

Mothers of disabled children are even more isolated than most other mothers (Read, 2000, p.56), and due to their child’s disability they may have less access to informal support systems than other mothers (Read, 2000, p. 56). Many mothers take fewer trips outside of their home because of concerns about the public’s reaction to their child’s behaviour (The Beresford Report, 1995, as cited in Read, 2000, p.58). The same report also found that the main reason why families of a child with special needs move homes is related to difficulties with their neighbors regarding their child’s disability (as cited in Read, 2000, p.59).

Seligman and Darling state that the aspect of family life most affected by having a child with autism is family recreation – because parents do not want to take their child with autism out in the community (1997, p. 66).

One of the key themes in a qualitative study involving twelve mothers of a child with special needs was the constant need of these mothers to be case-managers and advocates for their child – often under difficult circumstances (Read, 2000, p.1). Many of these twelve mothers ironically reported that dealing with the agencies that were there ostensibly to support them and their children brought about “some of the most stressful and difficult experiences that they had” (Read, 2000, p. 34).

**Review of Key Qualitative Studies**

Brown et al conducted both an extensive quantitative and qualitative study on the experiences of Australian mothers. The qualitative part of the study included semi-structured home interviews with 90 mothers – 45 depressed and 45 non-depressed mothers.
The authors failed to analyze the data into any coherent and concise themes. Instead they provided limited quotes from the mothers under a great many different headings. An informal review of some of the key headings included mothers feeling: “confined” (p. 165); “physically and emotionally fatigued” and “run down” (pp. 168-169); “never having a break” (p. 205); and feeling inadequate (p. 178). The study, while very extensive and enlightening about the experiences of mothers of very young typical children, does not shed any light on any aspect of the experiences of mothers of special needs children or mothers of children with autism.

Read (2000) conducted a qualitative study of twelve mothers of a child with special needs. The study’s design, however, failed to fully capture these mothers’ actual experiences. Instead, Read went into this study with a preconceived notion of what she was looking for and to gather information about these mothers’ experiences in only one very small area that Read had prematurely assumed was the key theme of such mothers’ experiences. She states: “The interviews were structured only insofar as I had determined (italics added) the three key areas for discussion: the particular role of mothers; explaining work with their sons and daughters; and negotiating and mediating with other people (Read, 2000, p. 17).” None of the twelve mothers interviewed had a child with autism; instead all of their children’s disabilities were medically and not behaviorally oriented. This study, while very informative about one aspect of mothers’ subjective experiences of caring for a child with special needs, did not address the overall experiences of such mothers and did not explore the experiences mothers of a child with autism have with their support system.

Rannveig Traustadottir (1991) did a qualitative study with a feminist perspective on
the experiences of mothers caring for a child with special needs. Fourteen families were interviewed. The children’s disabilities were only partly described. Several appeared to have had a mental handicap and others had conditions such as cerebral palsy, a seizure disorder, or a visual impairment. Only one child had autism.

She discovered four themes. The first theme was that some mothers found this experience to be “empowering”. Such mothers did extensive volunteer work in the disability field and found that this gave their life a “sense of a mission” that they felt they would not have had otherwise. The second theme was that some mothers found caring to be “disruptive”. These mothers felt restricted by their caregiving role, such as having to put their career on hold. The third theme was that some mothers felt that caring was “simply one part of their life.” All of these mothers lived in poverty. Referring to these mothers, Read writes:“ Having enough food and a home were issues of more immediate concern (p. 218).” The fourth theme was related to the experience of just one of the mothers who felt forced to become a “supermom.” This was the only mother in the study who combined a career with full-time parenting. This mother spoke about how exhausted she was, how she was forced to get by with very little sleep, and how she was forced to become an “expert manager.”

This was the only study that I could locate that took both a qualitative and a feminist approach to exploring any aspect of the experiences mothers have caring for a child with special needs. The feminist analysis of this study, however, was quite superficial. Traustadottir failed to link many of her findings to other relevant feminist research findings, such as the “absent father” syndrome, self-neglect of mothers as a way of coping, or to
mention anything about the institution of motherhood. Only one child in this study had autism – leaving the voices of mothers of a child with autism still silent and unheard.

**Summary**

This review of the feminist literature on motherhood revealed the bleak and harsh conditions for mothers, a reality that is only now beginning to be exposed. However, what has begun to be told of the powerful story of these oppressive conditions is focused almost exclusively on mothers caring for a child/ren without a disability. There has been extremely little research into any aspect of the subjective experiences of mothers caring for a child with special needs. To date, there does not appear to have been a gender-sensitive qualitative research study on any aspect of the experiences of mothers caring for a child with autism, which is the focus of this study. Before I share the experiences of the mothers in this study, I will first discuss, in the upcoming chapter, the methodology used in this qualitative research study.
CHAPTER 2  METHODOLOGY

In this chapter I will discuss the various research methods employed in this study. The design of this exploratory qualitative study uses an eclectic approach that primarily draws on feminist research principles and design and to a lesser degree on the principles and procedures of the qualitative research tradition of phenomenology.

CONCEPTUAL FRAMEWORK

A Feminist Approach

Qualitative research, such as phenomenological research, has become very popular in feminist research and is very compatible with feminist objectives and principles (Creswell, 1998, p. 19; Kvale, 1996, p. 72; & Van Manen, 1998, pp. xvi-xvii). Feminist research is guided by feminist theory. Feminist researchers almost always utilize feminist theory to frame questions and interpret their data (Reinharz, 1992, p.249). This study has been guided primarily by the feminist literature on motherhood and, to a lesser extent, the feminist literature on mothers’ experience of caring for a child with special needs.

Feminist research also involves the reader. Reinharz writes: “Many feminist researchers who interview include quotations from the interviews in the research product in order to give the reader a sense of these people. When the interviewees ‘speak for themselves’ or ‘use their own voice,’ the reader is better able to understand (1992, p. 267).” This study provides many direct quotes from the participants.

I will now go on to explain my relationship with the participants and how I addressed another of Reinharz’s themes of feminist research – involving the participant in the research process. There is no agreement among feminists about what type of
relationship the researcher should have with participants. The relationship that I aimed for was one that was non-exploitive, respectful, actively involved the participant in providing their expert feedback on my analysis, allowed the participant’s expertise to dictate the content of the interview, and allowed me to explicitly state that I saw myself more as a learner and listener rather than as an “expert” researcher (Reinharz, 1992, p.29). I followed-up my involvement with each participant by sending a hand-written thank you note (Moustakas, 1994, p. 109).

**Developing an Eclectic Approach to Qualitative Research**

My research question was: “What are the experiences mothers of a child with autism have with their support network?” A phenomenological research study seeks to explore the everyday lived experience people have of a phenomenon – like mothering a child with autism (Van Manen, 1998, p. 7). Van Manen writes: “Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences. Phenomenology asks, ‘What is this or that kind of experience like?’ (1998, p. 9).” Because there were no prior qualitative studies in the literature exploring the experiences mothers of a child with autism have with their support network, an eclectic study drawing on both feminist and phenomenological research design and principles devoted to understanding and exploring such mothers’ lived experiences best lent itself to examining this question (Creswell, 1998, p. 98).

Phenomenological research, however, like other qualitative research traditions, lacks any clear methodology and procedures (Coffey & Atkinson, 1996, p. 2; Kvale, 1996, p. 13;
& Van Manen, 1998, p. 30). Rather, its method requires an ability to be reflective, insightful, and constantly open to experience (Van Manen, 1998, p. xi), and even to “invent” research techniques and methods unique to one’s study (Van Manen, 1998, p. 30). While my overall design most closely resembles a feminist research approach, I chose a more eclectic approach for the analysis portion of the study so not to restrict myself to the narrow confines of just one methodology (Coffey & Atkinson, 1996, pp. 12-16; & Creswell, 1998, p. 21). In fact, such an eclectic analytical approach is the norm (Kvale, 1996, p. 203). In developing such an eclectic approach, I studied, critiqued, and integrated those aspects from the works of Van Manen (1998), Moustakas (1994), Kvale (1996), Creswell (1998), and Coffey & Atkinson (1996) that I thought were most meaningful, pragmatic, realistic, and consistent with my overall design.

In the end, my analysis relied mainly on three key features: (1) a phenomenological use of themes; (2) a hermeneutic understanding of the importance of moving beyond the confines of the data alone to a more interpretive analysis that is largely based on feminist theory on motherhood; and (3) a post-modern understanding about the complexity, diversity, and contradictory view of experiences in general and the legitimacy of multiple valid interpretations of the data (Coffey & Atkinson, 1996, p. 163; Creswell, 1998, p. 75; & Kvale, 1996, p. 211). Coffey and Atkinson write: “There is no one single ‘correct’ interpretation of a social setting or event. Qualitative research captures multiple versions of multiple realities (1996, p. 163).”
RESEARCH PROCESS

Sample

My unit of analysis was mothers who are primary caregivers of a child with autism. I interviewed eight such mothers for this study. Typically, qualitative studies, with a design and purpose similar to this one, use sample sizes ranging from three to ten participants (Creswell, 1998, p. 122). While the concepts of generalizing results to the greater population and using sampling strategies that are representative of the larger population are the focus of quantitative studies, these concepts have much less value and relevance in qualitative studies (Creswell, 1998, pp. 110-111). Rather, in qualitative studies, the goal is for the research findings to be applicable to other contexts and to other subjects (Lincoln & Guba, 1985, p. 290). As Creswell states, it is not the quantity of participants that is important in qualitative studies, but rather “the important point is to describe the meaning of a small number of individuals who have experienced the phenomenon (1998, p. 122).” In other words, in qualitative research the focus is more on quality and depth of analysis of a relatively few number of participants as opposed to a focus on the quantity of participants. For all the above reasons, my sample size of eight mothers for this study was appropriate.

I used a purposeful sampling approach known as criterion sampling (Maxwell, 1996, p. 70). Criterion sampling can be defined as “a sampling strategy in which particular settings, persons, or events are selected deliberately in order to provide important information that can not be gotten as well from other sources (Maxwell, 1996, p. 70).” The criteria that I used in selecting mothers for this study were: (1) mothers who had a child with autism; (2) mothers who self-identified themselves as the primary caregiver for their
child with autism; (3) mothers whose child with autism was diagnosed as such at least two years previously; (4) mothers who identified themselves as being in a place of emotional readiness in relation to their ability to share their experience; (5) mothers who were not a client of mine through the MCFD; and (6) mothers who were able to provide informed consent.

I accessed my sample of such mothers through a technique called snowballing. Snowball sampling can be defined as a sampling strategy that "identifies cases of interest from people who know people who know what cases are information-rich (Creswell, 1998, p. 119)." Upon locating a participant, I asked her if she knew of anyone else who might be interested, and whether that person met the criteria and would be able to provide me with the information needed. I then gave this third party a letter of invitation to pass on to this prospective participant. The prospective participant was then asked to call me directly if she was interested in participating. The original third person was not told whether or not the prospective participant decided to participate, thus ensuring confidentiality for this new participant. Also, since the prospective participant was asked to call me instead of me initiating a call to her, there was no pressure placed on this person to participate, thus ensuring voluntary participation.

**Data Collection**

The use of semi-structured interviews has become the principal (italics added) means by which feminists have sought to achieve the active involvement of their respondents in the construction of data about their lives.... Feminist researchers find interviewing appealing because it allows researchers to directly hear people's ideas, thoughts, and feelings in their own words, rather than the previous ways of ignoring women's ideas altogether or having men speak for them... Interviewing also is consistent with the feminist practice of not
controlling the direction and content of a participant’s story and to enhance the researcher’s sense of connectedness with the participant (Reinharz, 1992, pp. 18-20).

The data was collected by means of semi-structured face-to-face interviews (Moustakas, 1994, p. 114). As is the standard practice, recording of the interviews was done using a tape recorder (Kvale, 1996, p. 160). For the first two participants a second interview was required in order to finish asking the interview questions. With both of these participants, the first and second interview took approximately one and half hours, bringing the combined total time to three hours to interview each of these two mothers. The following six participants were interviewed just once. Each of these interviews took approximately two to two and a half hours to complete.

Each woman was given a choice about the time and location of the interview so as to maximize convenience, comfort, and safety. Seven of the eight interviews were conducted in the mother’s home. For two of these interviews the whole family was home when I first arrived, giving me a chance to meet and interact with the father, siblings, and the child with autism. The fourth interview was conducted in a private meeting/interview room that the mother reserved at her place of work.

Once at the interview, and after rapport had been established to some extent (Moustakas, 1994, p. 114), I reviewed once again the purpose and focus of the research study (Moustakas, 1994, p. 103). I then asked the participant to sign the consent form prior to beginning the interview. Just prior to beginning the interview, I stated that my hope was to capture their experience in as complete and unobstructed a way as possible. As such, I
mentioned that I saw my role as that of a passive participant but active listener. With the exception of prompting and clarifying questions, I tried to save questions, as far as possible, until the latter part of the interview so as to minimize the number of distractions. As Creswell notes: “A good interviewer is a listener rather than a speaker during an interview (1998, p. 125).” All eight mothers were very articulate and appeared to have little difficulty directing the flow and content of the interview in a very smooth, eloquent, and at times moving and emotional way.

**Research and Interview Questions**

Research questions formulate what the researcher wants to understand, while interview questions are what the researcher asks participants in order to gain that understanding (Maxwell, 1996, p. 74). My main research question was: “What are the experiences mothers of a child with autism have with their support system?” This question focuses on the subjective experiences of such mothers and about what meanings they have developed about their experiences. As stated in chapter one, this exploration of the emotional and subjective experiences of mothers is neglected in the current literature. My main research question is as broad, open-ended, and non-directional as possible because the primary purpose of my research is to begin exploring this heretofore unexplored topic (Creswell, 1998, p. 19 & pp. 99-100).

This main research question, as is common in qualitative research, begins with “what”, as opposed to quantitative approaches that often involve “why” questions. Creswell writes:
In a qualitative study, the research question often starts with a ‘how’ or ‘what’ so that initial forays into the topic describe what is going on. This is in contrast to quantitative questions that ask ‘why’ and look for comparisons of groups...or a relationship between variables, with the intent of establishing an association, relationship, or cause and effect (1998, p. 17).

An interview guide was used to: (1) assist note-taking during the interview; (2) organize my thoughts under key headings; (3) organize information needed for starting off and concluding the interview (Creswell, 1998, p. 126); and (4) assist with the efficient use of the limited time available (Moustakas, 1994, p. 103).

**Ethics**

**Informed Consent and Voluntary Participation**

All participants were informed about the overall purpose of the study and about the possible risks and benefits of participating so that they could make an informed decision about whether or not to participate (Creswell, 1998, p. 115; & Kvale, 1996, p. 112). Voluntary participation issues were addressed by stressing with each participant that they could withdraw from the study at any point (Creswell, 1998, p. 115; & Kvale, 1996, p.112) and by having prospective participants initiate a call to me to express their willingness to participate, rather than me initiating a call to them and thereby possibly pressuring them to participate. Also, in order to avoid any risk of coercion to participate (Kvale, 1996, p.112), I did not ask any of my MCFD clients to participate.

**Confidentiality**

Confidentiality in qualitative research studies implies that private data identifying the participants will not be reported (Kvale, 1996, p.114). The participant’s identity and
privacy were safeguarded by using pseudonyms instead of their names for themselves and by changing any identifying features in their reported quotes (Creswell, 1998, p. 132; & Kvale, 1996, p. 114). Transcripts and floppy disks of the interviews were stored in separate and secured locations with only myself having access to this data (Kvale, 1996, p. 172). As promised to the mothers, these floppy disks were destroyed soon after the interviews were transcribed and checked for accuracy, and the transcripts were shredded after the analysis was completed.

Consequences

Kvale states: “The ethical principle of beneficence means that the risks of harm to a subject should be the least possible (1996, p. 116).” This was addressed by making sure that only mothers who were emotionally ready for such an interview were chosen. This ruled out mothers whose child was diagnosed with autism two years or less ago. It was felt that such mothers may still be emotionally dealing with too much and that a potentially powerful and stirring interview on this topic may be too much for them at this point.

Secondly, steps were taken to minimize any marital discord stemming from this interview. While remaining supportive of mothers’ concerns and frustrations about their partners’ abdication of responsibilities, I deliberately did not facilitate “husband bashing.” I did this for two reasons. Firstly, this was not a therapy session (Kvale, 1996, p. 156); and secondly, I did not want to be responsible for further friction between partners as a result of my interview. Kvale writes: “In research, however, [as opposed to therapy] it is the interviewer who has sought out the interviewees; they have not asked for interpretations leading to
fundamental changes in the way they understand themselves and their world...It may be unethical to instigate new self-interpretations or emotional changes (1996, p. 156)."

**Independence of Findings**

MCFD was not approached as a sponsor for this study in order to avoid any censoring of unpleasant findings about MCFD’s role in such mothers’ lives. Kvale writes: “The independence of research can be co-opted from ‘above’...by the funders [or sponsors – i.e. agencies that review and support a study and allow access to its clients] of a project...[Such] ties may lead the researcher to ignore some findings and to emphasize others to the detriment of as full and unbiased an investigation of the phenomena as possible (1996, p. 118).”

**Data Analysis**

“Data analysis is not-off-the-shelf; rather, it is custom-built, revised, and ‘choreographed’. Qualitative researchers ‘learn by doing’ (Creswell, 1998, p.142).”

As a whole, qualitative analysis means different things to different researchers; there is no one right way of conducting analysis (Coffey & Atkinson, 1996, pp. 6-7; & Creswell, 1998, p. 140). Tech reviewed these various methods of doing qualitative analysis and identified several “features” common across the various methods. He remarked:

...analysis is a cyclical process and a reflexive activity; the analytical process should be comprehensive and systematic but not rigid; data are segmented and divided into meaningful units, but connection to the whole is maintained; and data are organized according to a system derived from the data themselves. Analysis is, on the whole, an inductive, data-led activity (as cited in Coffey & Atkinson, 1996, p. 10).

As described earlier, I developed an eclectic approach for my analysis. This eclectic analytical process involved six key stages. The following is a very brief outline of these
stages. Each stage will be elaborated on later. Stage one – getting a sense of the whole – involved reading the whole transcript, without stopping, to get a sense of the whole. Stage two – coding – involved reducing the data into manageable pieces that could be organized and categorized to assist with the analytical process. This second stage involved four key steps: (1) reading the transcripts, one line at a time, to identify key statements that speak to the important dimensions involved in the experiences of mothers caring for a child with autism; (2) condensing these key statements to a summary of their central idea – thus creating meaning units; (3) cutting out these key statements and meaning units from the transcript and then placing them in piles of other clippings with shared characteristics; and (4) labeling these piles/categories based on their shared characteristic. Stage three – searching for themes – involved reflecting on these codes and transforming them into themes based on observed patterns. Stage four – interpretation – involved moving beyond the data to a more interpretive process, guided by the feminist literature. The fifth stage, the search for underlying core themes, involved looking for larger, more abstract themes that revealed the underlying characteristics on these many micro-themes into just three core themes. The sixth and final stage – writing as analysis – involved trying to transform these core themes into metaphorical statements and then writing up the results.

The following description of how analysis was done has been artificially and simplistically categorized into separate steps for clarity of description. In reality, my analysis, as with most qualitative research studies, evolved over many different stages of the research process, and the stages became blurred – with some aspects of analysis done simultaneously (Coffey & Atkinson, 1996, p. 9; & Van Manen, 1998, p. 34). For example,
although the analysis steps outlined below suggest a seamless and unbroken process of analysis, there was actually a break of over a year in formal analysis between the first four interviews/transcripts and the last four interviews/transcripts. During this break, I immersed myself in a detailed literature review of feminist theory on motherhood. The increased insight that I gained as a result of this literature review into the dynamics and issues involved in motherhood in general, though not explicitly stated in the analysis outline, affected subsequent interviews and my interpretation of the data.

Preparation

Each interview was taped and later transcribed by a professional transcriber. The transcriber was instructed to transcribe the interview verbatim. She was provided with a brief list of symbols to use to indicate certain basic participant responses, such as a pause from the participant. The transcript page was divided down the middle of the page – with the text on the left side and blank space on the right, allowing for notes and meaning condensation and/or reflection (Kvale, 1996, p. 192). Once returned to me, I read the transcripts while listening to the tapes myself to make the necessary corrections.

Before analyzing the transcripts I used a phenomenological technique called "bracketing" or "the epoche process" to minimize any preconceived ideas or expectations that I had about certain categories or themes that may be involved in mothering (Kvale, 1996, p. 54; Moustakas, 1994, p. 22; & Van Manen, 1998, p. 47). The idea is to be as open-minded, naïve, and receptive as possible, while listening to and later analyzing the experiences of these mothers (Moustakas, 1994, p. 22). For example, one expectation that
I had about mothers who are primary caregivers of a child with autism was that, as stated in the literature, they would experience significant hardship in this role and would likely feel some resentment towards their partners about this unequal distribution of household and child care responsibilities. In bracketing myself from this expectation, I became consciously aware of this preconceived idea of mine, and as a consequence had to constantly remind myself to be open to hearing and reading the experiences of these mothers from their perspective, not mine, and to be prepared to acknowledge and report when mothers felt content with the role they and their partners were playing.

**Getting a Sense of the Whole**

I then started the first formal concrete stage of analyzing by “immersing myself” in the reading of the interview transcripts, one transcript at a time, from beginning to end, without stopping, in order to get a “sense of the whole” (Creswell, 1998, p. 143; Giorgi, 1979, p. 83 as cited in Moustakas, 1994, p. 13 & p.18; Kvale, 1996, p. 194; & Maxwell, 1996, p. 78). Throughout this initial reading of the whole, I was searching for recurring patterns (Kvale, 1996, p. 204), developing tentative ideas about categories and relationships (Maxwell, 1996, p. 78), and asking myself, from the mother’s perspective, what is going on in the lives of these mothers as they care for their child with autism? (Coffey & Atkinson, 1996, pp. 8-9).

**Coding**

Having read each transcript from beginning to end, without stopping, to get a sense of the whole, I then took the next step of reading each transcript again, but this time one line
at a time (Giorgi, 1979, p. 83 as cited in Moustakas, 1994, p. 14). This more detailed step begins the process known as coding. Coffey and Atkinson give this definition of coding:

Researchers need to be able to organize, manage, and retrieve meaningful bits of data. The usual way of going about this is by assigning tags or labels to the data, based on our concepts. Essentially, what we are doing in these instances is condensing the bulk of our data sets into analyzable units by creating categories with and from our data. This process is usually referred to as coding (1996, p. 26).

Coding generally is used to break up and segment the data into simpler, general categories; to expand and tease out the data to formulate new questions and levels of interpretation (Coffey & Atkinson, 1996, p. 30); to assist with analyzing and searching for commonalities, differences, patterns, and structures (Coffey & Atkinson, 1996, p. 29); and to conceptualize the data, providing tentative answers about the relationship among and within the data, and discovering the data (Coffey & Atkinson, 1996, p, 31). Put in another way, “segmenting and coding data enable the researcher to think about and with the data (Coffey & Atkinson, 1996, p. 31).”

The coding process involved three key steps. In the first step, a label or code was given to a complete idea or statement that was significant from the transcript, the size of which varied from a phrase to several paragraphs (Creswell, 1998, p. 32; Miles and Huberman, 1994, as cited in Coffey and Atkinson, 1996, p. 28). As I read the text line by line, I asked myself these questions: Are there any phrases that stand out from the rest? Can I select some sentences or part sentences that seem to be thematic of the experiences of such mothers? What statements or phrases seem particularly revealing about the experience of such mothers? In what way does this sentence, idea, or statement reveal something about
the experiences of such mothers?” (Van Manen, 1998, p. 93). Statements that were clearly irrelevant to my research question were discarded (Kvale, 1996, p. 190; & Moustakas, 1994, p. 97).

I used a highlighter to mark the key relevant statements, and in the margins I wrote reflective memos about my interpretations about these statements (Coffey & Atkinson, 1996, p. 29; Creswell, 1998, p. 140; & Van Manen, 1998, p. 93).

I also maintained a journal in which I wrote further memos to myself. Maxwell writes: “Memos not only capture your analytical thinking about your data, they actually facilitate such thinking, stimulating analytical insights (1996, p. 78).”

In the second step of coding, I interpreted and summarized the central idea of each key statement unit into a condensed meaning unit. This condensation was written down on the right side of the page (Creswell, 1998, p. 32). At this stage of analysis, these condensed meaning units were still primarily expressed in the concrete language of the mothers themselves (Coffey & Atkinson, 1996, p. 36). I continuously compared and related these evolving condensed meaning units to each other and to the sense of the whole (Giorgi, 1979, p. 83 as cited in Moustakas, 1994, p. 14; & Kvale, 1996, p. 204). Each of these reduced meaning units were then “interrogated for what it reveals” (Giorgi, 1979, p. 83 as cited in Moustakas, 1994, p. 14; Kvale, 1996, p. 194; von Eckartsberg, 1986, p. 27, as cited in Moustakas, 1994, p. 14) in terms of the specific purpose of the study.

In the third step involved in coding, I returned to the beginning of each transcript and began cutting out each of these highlighted key statements and their accompanying meaning condensations and placing them into different piles (Coffey and Atkinson, 1996, p.
45; & Kvale, 1996, p. 188). Both the statement and the meaning condensation (i.e., my interpretation of the central idea of the statement) were cut out as one whole clipping. The piles were identified by an envelope that was labelled with the tentative code/name for that particular category/pile.

**The Search for Emerging Themes**

After identifying all of the meaning units and coding them into different categories/piles, I went the next step of identifying and developing them into tentative and evolving themes, between twelve and fifteen in number (Creswell, 1998, pp. 31-32; Kvale, 1996, p. 30; Moustakas, 1994, p. 97 & p.130; & Van Manen, 1998, p. 79). In this theme development stage, I moved up one step from restricting myself from simply looking at micro level codes mainly from a descriptive form and from within the actual words of the participants (Van Manen, 1998, p. 93) to the next phase of looking at the data for some larger overarching themes that would lead to fewer, more broad, coherent and abstract or conceptual themes (Moustakas, 1994, p. 98) – subsuming the particulars under the general and abstract (Kvale, 1996, p. 204; & Moustakas, 1994, p. 97). This led to the collapsing of previously separate micro themes into larger underlying themes once I became more familiar with their underlying common conceptual idea. Themes that upon further reflection seemed to be redundant were discarded (Giorgi, 1979, p. 83, as cited in Moustakas, 1994, p. 14).

This refining process involved intensive questioning and interrogating of the data. Some of the questions asked were: What is missing in these women’s stories? What is surprising about their stories? Comparisons were constantly made between the participants
in terms of similarities and differences. One key strategy that I used was to develop a
detailed matrix chart that listed all the key points gathered from each mother. With this
chart I could tick off which mothers reported what key findings. At a glance I was able to
see and count where certain themes and patterns were. Throughout this comparison
process, I analyzed the data in terms of what were the relationships among the categories.
Two ways in which I tried to do this were to examine the data for repeating and common
patterns of issues, concerns, and ideas, and then to map out and draw several different
diagrams that tried to capture what I was noticing (Coffey and Atkinson, 1996, p. 46;

This process of constant refining, questioning, reflecting, memoing, diagramming,
and comparing led to the identification of more and more abstract all-encompassing themes.
The prior stand-alone themes were either combined, had some common underlying
characteristic identified, or became one of up to six sub-themes of a larger theme. This very
long and drawn out process eventually resulted in three core themes. These core themes,
however, were still confined to a description of the data alone and did not attempt to search
for further insight using current theory.

Moving Beyond the Data to Interpretation

It is vital to recognize that the generation of ideas can never be dependent on the data alone.
Data are there to think with and to think about. As we have indicated, ideas about our data
go beyond the data. We should bring to them the full range of intellectual resources,
derived from theoretical perspectives, substantive traditions, research literature, and other
The move from coding to interpretation is a crucial one (Coffey and Atkinson, 1996, p. 46). Some of the analytical interrogation tactics and strategies include: varying the frame of reference; employing polarities and reversals; approaching the phenomenon from divergent perspectives (Creswell, 1998, p. 150); using “imaginative variation”, different roles, functions, or positions (Moustakas, 1994, pp. 97-98); looking for patterns, themes, and regularities as well as contrasts, paradoxes, and irregularities; questioning the relation between variables; finding conceptual and theoretical coherence in the data; “playing with” and exploring the codes and categories that were created (Coffey and Atkinson, 1996, pp. 46-47); following up on surprises; looking for negative evidence; making if-then tests; replicating a finding; and checking out rival explanations (Kvale, 1996, p. 242). In other words, coding and categories are used to think with and not to remain anchored in the data/transcripts (Coffey and Atkinson, 1996, p. 49).

At this point I continually took steps back from both the data and my emerging set of themes to try and look at these ideas from a fresh and different perspective. One way I tried to do this was by comparing these emerging themes with both well-established feminist understandings of being a mother and primary caregiver and less well-established feminist ideas and theories (Coffey & Atkinson, 1996, p. 140; & Kvale, 1996, p. 204). Feminist theory, or other theory the researcher holds, can and should be used when interpreting the data. Coffey and Atkinson write: “There is no doubt that theoretical ideas can and should inform the coding of data (1996, p. 142).” Having completed this comparison of my findings with the current feminist literature on motherhood I ended up with three core themes. Each theme was then reviewed for relevance to the entire transcript
Writing and Reporting as Part of Analysis

Analysis is not simply a matter of classifying, categorizing, coding, or collating data...Most fundamentally, analysis is about the representation or reconstruction of social phenomenon...we do not merely report what we find; we create accounts of social life, and in doing so we construct versions of the social worlds and the social actors that we observe (Coffey & Atkinson, 1996, p. 108).

I then attempted to translate each of these core themes into a vivid metaphor statement to make them more easily understood and remembered (Coffey and Atkinson, 1996, p. 159; Creswell, 1998, p. 146; & Kvale, 1996, p. 275). Coffey and Atkinson write: “The very logic of qualitative research, with its emphasis on comparative methods, calls repeatedly for metaphorical or analogical thinking, reading, and writing (1996, p. 159). Using metaphors in qualitative research also allows for a “richer” and “more complete” way of reporting the findings than simple description of the data (Miles and Huberman, 1994, as cited in Kvale, 1996, p. 275). Unfortunately, while I was able to use quite abstract concepts, such as abandonment and having to be a “supermom,” when writing up these core themes I never was able to reach the point of transforming them into vivid and complete metaphors.

In closing, it should be emphasized that analysis is never complete, there can always be further findings derived from the data. Coffey and Atkinson write: “In the fullness of time, some of the ideas might be discarded and modified. Others might be developed and
documented more fully. Analysis is never complete. There are always more ideas and more lines of inquiry open to us than we can ever hope to exhaust (1996, p. 146).” The next step involved trying to establish the trustworthiness of this analysis.

**Verification Procedures**

There is no agreement among qualitative research scholars about the importance of verification, the definition of it, and the procedures for establishing it (Creswell, 1998, p. 197; & Kvale, 1996, p. 242). Creswell proposes eight “verification procedures” that can be used to help ensure the trustworthiness of a research study (1998, pp. 201-202). He suggests that any research study use at least two of these procedures (Creswell, 1998, p. 203). For this study I used two procedures: member checks (Kvale, 1996, p. 242; Maxwell, 1996, p. 94; Moustakas, 1994, p. 18; & Reinharz, 1992, p. 37) and ensuring rich and thick description of the participant’s experience (Maxwell, 1996, p. 95).

Member checks is a process whereby the researcher goes back to the participants to clarify the accuracy and comprehensiveness of data taken earlier and to seek feedback on the researcher’s developing analysis and interpretation of earlier data (Creswell, 1998, pp.202-203; Moustakas, 1994, p. 18; & Reinharz, 1992, p. 37). As cited in Creswell, Lincoln and Guba (1985) consider this technique to be the “most critical technique for establishing credibility (1988, p. 202-203).” I completed detailed member checks with six of the eight mothers. I could not do so with the remaining two mothers because they had moved out of the area since I first interviewed them over two years ago. For the remaining six mothers they all very strongly agreed with my analysis as presented to them. The only exceptions
were two mothers who disagreed with one of the sub-themes concerning the role, or lack of, their partners played and one of these same mothers who disagreed with the theme concerning the burdens and hardships mothers experience as “supermoms.”. I will discuss these exceptions further in the following chapter.

The second primary means of establishing credibility for my study was the use of rich and thick descriptions. Rich and thick description can be defined as data and reporting of findings that are detailed and complete enough to provide the reader with a full and revealing picture of what is going on, so that the reader can make some informed analysis about the credibility of the researcher’s conclusions (Creswell, 1998, p. 203; & Maxwell, 1996, p. 95). Much of the upcoming findings chapter consists of detailed and comprehensive quotes from the mothers.

**Summary**

In summary, this exploratory qualitative research study into the experiences mothers of a child with autism have with their support system was an eclectic approach that primarily drew on feminist research principles and to a lesser extent, on ideas from phenomenological research, such as the use of themes to explore experiences. I also employed a hermeneutic understanding of the importance of moving beyond the confines of the data alone to a more interpretive analysis, based largely on feminist theory on motherhood and a post-modern understanding about the complexity, diversity, and contradictory view of experiences in general and the legitimacy of multiple valid interpretations of the data (Coffey & Atkinson, 1996, p. 163; Creswell, 1998, p. 75; &
Kvale, 1996, p. 211). Again, as Coffey and Atkinson write: "There is no one single 'correct' interpretation of a social setting or event. Qualitative research captures multiple versions of multiple realities (1996, p. 163)." In this next chapter I will present my version of reality for these particular mothers at this particular time.
CHAPTER 3 FINDINGS

This study identified three themes about the experiences mothers of a child with autism had with their support system. These themes are: (1) Ignored; (2) Abandoned; and (3) Burdened ‘Supermoms.’ Each theme had between three to six sub-themes.

Because the community of families that have a child with autism in the Lower Mainland is very cohesive, organized, and connected, I significantly distorted superficial demographic information about the families in this study when either quoting them or describing their situation. This is being done to minimize the chance of any parent or professional involved with this community recognizing the referenced/quoted family. The mothers in this study bared their hearts and souls knowing that I assured them confidentiality. Accordingly, I will not provide a description of the key characteristics and demographics of each mother and her family.

I have also assigned each mother and their child a pseudonym. The closest that I will come to placing the individual experiences of specific mothers in context is to assign their pseudonym based on the main theme or characteristic of their individual experience. I will give just typical and random pseudonyms for each mother’s partner and child(ren). If I gave pseudonyms for the partners and child based on their overall theme or characteristic, this might be enough for some professionals or other mothers to be able to identify which family I am describing.

I have given to each mother the standing of “Ms.” as opposed to “Mrs.” to symbolize the nearly complete absence of each of their husbands from family life. The first mother I
have called Ms. 'Pissed-Off' because she was so bitter, angry and "pissed-off" with many people in her life, but mainly with her husband. The second mother I have called Ms. Barely Survived because her situation was so difficult, and she said, "I don’t know how I survived." The third mother I have called Ms. Guilty because her life and her life’s actions were consumed and dictated by guilt. The fourth mother I have called Ms. Single because she repeatedly talked about feeling like a single parent since her husband spent nearly all of his non-working hours on the computer locked away in a different room away from his family. The fifth mother I have called Ms. I’m OK because she claimed to be fine with her husband’s role and involvement despite his being nearly completely absent from the family. The sixth mother I have called Ms. Supermom because she herself used that metaphor to describe how she was forced to try and become “Superwoman” to meet all of the impossible demands placed on her. The seventh mother I have called Ms. Abandoned because she was so angry about how the Ministry for Children and Family Development had abandoned her and her family. The eighth and final mother I have called Ms. Ignored because of her constant frustration at having her concerns and issues about her son’s treatment dismissed and ignored.

**Theme One: Ignored**

“We [mothers] know our child better than any other expert because we’re the ones there twenty-four hours a day. We know what works and when to back off.”

The first theme identified was that, despite being often ignored, mothers, not professionals or others, are often the leading experts, not professionals or others. Without
exception, every mother experienced this theme quite strongly. The first sub-theme is that *mothers are often dismissed by partners and/or doctors about pre-diagnosis concerns*. The second sub-theme is that *mothers’ concerns are only heard after having been corroborated by others*. The third sub-theme is that *professionals often ignore mothers’ behavioural management expertise*.

**Sub-Theme 1A: Mothers are Often Dismissed by Partners and/or Doctors about Their Pre-Diagnosis Concerns**

In each mother’s situation it was the mother who initially noticed, was concerned about, and actively searched for the cause/diagnosis of her child’s strange behaviours. With one exception, the fathers not only did not actively assist in this search, nor share the mothers’ concerns, but often actually dismissed, ignored, minimized, or patronized the mothers for their legitimate concern. This was the experience of five of the eight mothers. For example, Ms. Pissed Off said: “He’d be like ‘oh, you read too much into it’ or ‘oh no, don’t worry about it. It’s not big of a deal.’ You know because he would always try to play it down… Chuck wasn’t an active participant in the whole process [search for a diagnosis] and probably because he thought that I was imagining it or it wasn’t as big of a deal as whatever.” Ms. Single said: “When I said I realized he’s different, my husband said you are thinking too much or you worry too much.” Ms. Barely Survived said: “And Anton said nah, nah, nah, he’s not autistic.” Ms. Ignored said: “He [partner] refused to listen to me [about her child’s strange behaviours].” Despite some mothers being dismissed by their
partners as worrying too much, all mothers persisted in their search for finding the cause of their child’s strange behaviour. Yet, when they approached their family physician, most of the mothers were dismissed once again.

One of the paramount principles of effective treatment of autism is early intervention. But before early intervention can begin, a child must first be correctly diagnosed. Yet, in six of the eight mothers’ experience, their child’s family physician either ignored their concerns about something being seriously wrong with their child’s development and/or actually blamed the mother for various things, such as overreacting. Yet, in each case, the mothers were the ones that were right all along, since their child was eventually officially diagnosed with autism. To this day Ms. Abandoned says she is tempted to go back to the original family physician whom she says made her so upset and frustrated when she was trying to find a diagnosis for her daughter. She said this doctor told her she was simply “an overanxious mother” and that there was nothing wrong with her daughter. Ms. Supermom tells of her experience of repeatedly not being believed by various doctors: She said:

So experiences with doctors that I have gone through was that they didn’t believe me, there was nothing wrong with him. We went from one doctor to another doctor, to a pediatrician, to a very specialist, that basically told me that I was expecting way too much of him and that I needed to quit work, lay back and, you know, let it go. Both [my husband] and I said at that time “What a quack”…So it was a lot of not believing. And then thinking that it was my fault, so then it was like, I was feeling guilty. Like it was me, okay. So, I was raising [my daughter] wrong. I was doing that.

Ms. Pissed Off had a similar experience of being told that she was just an overreacting mother. She said:

It seemed like they [doctors] weren’t hearing me. They weren’t listening to what I was
saying. So it’s I know all in the communication, but it’s, um, you know, physical things are different, that he seems to be this, or he seems to not enjoy life, he seems to be not eating, he seems to isolate himself. All those kinds of things. And they just don’t seem to get it right. “Oh, you’re just imagining this”, or “Oh, it can’t be that bad”, or “Oh, mom, don’t worry, you’re just over-reacting”. All that kind of crap, right.

Ms. I’m OK tells of several similar stories of being dismissed by doctors and one psychiatrist. In one story she shares at length her frustration of telling a doctor all of the various very odd behaviours that her daughter had, and how she doesn’t seem to interact with her or the father at all, only to be told that her daughter is likely deaf. Yet, Ms. I’m OK stated: “I said to him [the doctor] no, she’s not deaf… I said, but she does hear because she can be three rooms away and you put a video on, she comes running…. But that doctor, and I never went back to him, that was the last day that I ever saw him.” So, the majority of mothers shared very clear stories of being ignored by their partners and/or by doctors about their pre-diagnosis concerns.

Sub-Theme 1B: Mothers’ Concerns only Heard when Corroborated by Others

A second sub-theme is that mothers’ concerns are only heard when corroborated by others. Four of the eight mothers stated that their doctor(s) continued to ignore their concerns until someone else, presumably with some credibility that the mother lacked, corroborated the mother’s concerns, or until this other person and the mother actually unofficially diagnosed their child with autism themselves. Ms. Supermom continued to be “not believed” until the staff at her daughter’s daycare also shared their concerns about her
child’s behaviours. Ms. Pissed Off continued to be told “all that crap” by her doctor about “overreacting” until a Mental Health counsellor, referring to the DSM IV, asked her a series of questions, leading to the two of them together concluding that it was autism. She stated: “So even by the time I went to see Dr. Damov I already knew, because by that time I had come home, gone to the computer, done a whole bunch of research, and went yeah, this [autism] is it.” Ms. I’m OK told a story of how, recalling from an old Donna Parker book she read years earlier about a child with autism, she and a friend of hers were able to start putting the pieces together and “diagnosed “ her daughter with autism themselves. She went on: “ I said I’m beginning to think maybe it is autism. And she [her friend] was connected to the Internet, so she came back to me with a bunch of stuff she had read off the Internet, and at that point in time we said okay, this is what it is…we had come to the conclusion of autism. We diagnosed it. We did.” Ms. Ignored had a very similar experience. So, four of the mothers who reported in the earlier theme that they were ignored by doctors repeatedly about their concerns about their child’s behaviours and development were only finally listened to and eventually given an official diagnosis of autism after a third party had corroborated their story or they and some one else had unofficially diagnosed the child with autism. These stories also demonstrate that it was first and foremost the mothers who were the leading experts about knowing their child’s unique circumstances and in recognizing that something was indeed very wrong with their child since their child was eventually diagnosed with autism, thus showing that the mothers’ diagnosis had been correct all along.
Sub-Theme 1C: Mothers’ Behavioural Management Expertise Ignored

This next and final sub-theme speaks to how the mothers’ behavioural management expertise was often ignored by professionals. Once their child was finally diagnosed with autism, all of these mothers immersed themselves in self-directed research about autism. Through this process of research, trial and error and sheer determination, coupled with their already expert knowledge about their child’s unique personality, they developed considerable behavioural management expertise specific to their child with autism. Yet their valuable input to school professionals and various other professionals was often ignored.

I will begin by demonstrating how these mothers were in fact experts in dealing with their child’s behaviours. All eight of the mothers provided several or more examples or stories demonstrating that they eventually developed considerable self-taught expertise in managing their child’s day-to-day very demanding autistic behaviours. Because of time constraints, I will provide just a few examples. Ms. I’m OK shared multiple stories of how she designed her own informal behaviour programs to teach her non-verbal autistic daughter how to more clearly and effectively communicate to others what she wanted to get, that throwing tantrums was not an effective way of getting her wants known. Ms. Guilty talked about how being the only constant presence among the huge turnover in professionals, she “just figured it out my way…and worked it out my way”, designing and building her own picture schedule and choice board. Ms. Barely Survived said that the behavioural support suggestions she received were too general and not individualized enough to fit her daughter’s unique needs and circumstances. She states:
Uh, I think as things developed, I think that as a parent I became pretty jaded from the point of view of, uh, you became realistic, I think. A lot of suggestions. Probably that [those suggestions] were all the contact we had with people who were genuinely trying to help; I mean that was their field, and they’re sort of experts. It was too general, I think, and we kind of felt that we knew our daughter best, and we knew how to handle her and [we] worked it out as best we could... For a while there we had it worked down to a fine art, how to respond to different behaviours; and you know we got her toilet trained.

Despite building up considerable expertise about managing their child’s autistic behaviours, many of the mothers experienced having their expertise ignored. Ms. I'm OK shared multiple stories about having her behavioural expertise ignored. She gave as an instance a child psychiatrist who strongly criticized many of the strategies she developed for working with her daughter, for example, certain sign language strategies, even though in the end these strategies proved very successful. Ms. Ignored talked of her experience when group home staff ignored her behavioural management expertise. This led to a dangerous escalation in her daughter’s behaviours. It was not until the staff finally stopped their interventions and tried the mother’s suggestions that the child’s behaviours stabilized. Ms. Pissed Off, Ms. Supermom, Ms. Abandoned, Ms. Single Mom, and Ms. Barely Survived all shared several similar stories about having their behavioral management expertise ignored; how more times than not this led to a deterioration in their child’s behaviours; and how the situation often did not improve until the professionals gave up on their strategies and tried the mother’s strategies. Ms. Supermom said: “And they’ve just figured that out at school too. That everything is visual. I’ve told them that a long time ago. Keep trying to tell them that. Hands on. Show him. He can do it.” Ms. Single Mom shared multiple stories about how her child’s school team were completely unable to manage her child’s sexual grabbing
and exposing behaviours; how in fact their program only escalated the situation badly; and how they dismissed and ignored the very polite and diplomatic suggestions from this very soft spoken and gentle mother. The mother’s stress became so bad at the start of each school year that she routinely got her ulcer medication increased. She said: “Grade one, grade two, after grade three – a lot of stress. That is the time that I need more medication every year for stress to prevent getting the stomach ulcer when I have stress. I have pain, heartburn, and I have to take [the ulcer medication] for four years. I will get [a] prescription when the school year starts...and then after that like grade four, five, and six [the situation started] getting better; and also the teacher [became] more cooperative.” Ms. Abandoned, whose child was the oldest of all the autistic children belonging to the eight mothers, had seen it all, and knew that many of these professionals did not have the same insight and practical knowledge that she did about how to manage her child’s behaviours. She said:

You learn that a lot of these so-called professionals – whether it be the school system, the medical system – really have no clue; and when you really question them, they not only don’t have a clue, they don’t even have a typical child of their own to deal with. So they’re telling you how to deal with a child that’s extremely challenging behaviourally, and you’re sitting there going, “This isn’t going to work.” And they’re going, “You haven’t tried it.” [Which is as much to say] you haven’t burned yourself out in the last two weeks trying to accommodate my study, program or whatever it is this month.

In summary, the first theme of despite often being ignored, mothers, not professionals or others, are often the leading experts of their child’s autistic behaviours, speaks to the mothers’ experience of consistently being dismissed and ignored, only to see in the end that the professionals were simply wrong and that the mothers were correct all along. This dismissive response was their experience with their partners and doctors prior
to diagnosis and with a host of other professionals afterwards. When Ms. Abandoned, the most experienced of mothers, was asked to share some words of wisdom to other parents of a child with autism, she said: “I guess the biggest thing as a parent, period, and even more so as a parent of an autistic child, is that if you feel something is not right, you are generally right, and that it is really important that if you’re uncomfortable with something, that you act on it.”

**Theme Two: Abandoned**

“I feel like I’m alone and fighting the battle by myself.”

The second theme has three sub-themes. The first sub-theme is that *mothers are abandoned by their partners*. The second sub-theme is that *mothers are abandoned by their informal support system*. The third sub-theme is that *mothers are abandoned by their formal support system*. Every mother but one experienced strong feelings of abandonment in at least two of the three sub-themes, though to varying degrees and with emphasis in different areas. The other mother said that she only felt feelings of abandonment in one area.

**Sub-Theme 2A: Dud Dads: Housework, Childcare, and Case-Management**

In terms of support from fathers, in my opinion, every mother in the study was virtually abandoned by their partners who failed to fulfill their obligations in regard to housework, child-care, and all of the many and very demanding case-management tasks. This theme was very powerfully and emotionally experienced by six of the eight mothers.
The remaining two mothers (one who was a stay-at-home mother and the other who worked part-time) defended their partners’ complete lack of support by saying that they had the time to do these tasks while their full-time working partners did not.

For several of the mothers what minimal and inconsistent support they did receive from their partners came about only when support was asked for or demanded, or when the mother resorted to “nagging”. The amount of support given never seemed to exceed a minimal amount and was inconsistently given; and even this low level of support depended on the mothers having to do something proactive to receive it. Because of space limitations, for this particular sub-theme I will focus more fully on the experiences of just three mothers to show how pervasive and total this abandonment was.

Firstly, the experience of Ms. Pissed Off (so named because of her consistent anger towards her partner) showed how she, despite working full-time in a very demanding and stressful mental health job, was solely responsible for virtually all housework, child-care, and case-management tasks; that this grossly unfair situation greatly upset her; and that her partner carried on as if there was no problem. In the following quote, Ms. Pissed Off describes how she is completely responsible for all childcare responsibilities, such as coordinating the children’s appointments; how difficult it is to balance this childcare while still maintaining total responsibility for the house and working full-time; and how tiring it can be to do this childcare unceasingly. She stated:

Well, it’s all about inequality… But now we both work full-time and it’s that whole balancing thing, that it just gets so difficult, right? And taking the kids to the dentist and the eye doctors; and I just get tired every once in a while, and I just kind of shut-down…and then I’ll kind of re-energize myself and get back on track and get things going again. But for sure it’s me unless I specifically ask Chuck to do a particular task.
In fact, in terms of noticing and remembering all of the many different things that children constantly need, especially a child with autism, Ms. Pissed Off said: “He just assumes that if there’s anything for the kids that needs to be done, that I’ll take care of it.” In fact, Ms. Pissed Off’s partner was every bit as clueless about noticing any of the many household chores that constantly need to be done. She said: “I think, honestly, I think it bothers me more than it bothers him what the house looks like. That’s probably what it boils down to. Because we were separated for a period of time quite a few years back, and I heard just horrid stories about the house.” She then went on to share her feelings about this unequal burden of work and how she had pretty much given up trying to change the situation because she had tried for so long unsuccessfully. She said: “It hurts. It really bothers me…we’ve just had the same conversations and it’s just getting [going] around and around, and it doesn’t get you anywhere…I resent it… I feel like I’m alone and fighting the battle by myself.”

Ms. Supermom experienced some support from her partner but only if she continually ‘nagged’ him about doing some task. Her partner so completely abandoned her for a while that she had to give him an ultimatum. She said:

Well, I wish that he would do more. Like you know and when we talk about it, I get gosh, I’m tired of doing this, you’ve got to help me here, like come on…So, if I’m always on top of him and being a nag, there goes that nagging wife again, then he’ll do it but then he’s mad at me. So you don’t want to push it. But, if I don’t push it, then things won’t get done. No, he doesn’t do them.

She said that her partner, until given an ultimatum, had completely forgotten that he was a father and spouse. She stated:

…but then Brent got hooked on the internet and he lost focus of the family for a while. He
had no idea that me and Cody even existed. And so I called up the Internet service and I cut him off.... And I said you’ve got to learn that you’ve got a son here that you’ve got to take care of and I need a break...I said it’s either Cody and myself or you can take your computer and run.

In experiencing absolute and seemingly permanent abandonment, Ms Single Mom felt completely drained in her role as ‘single parent’. Like the other mothers, Ms. Single Mom shared a story in which she said that her husband was so completely uninvolved in all aspects of housework and childcare that she said she felt like “a single parent”; that she often “want[ed] to separate from [her] husband”; and that, like Ms. Supermom, she too told her husband to either “take [his] computer with [him] and rent a room outside” or become a more involved parent and partner. She gave the following graphic and powerful description of a completely absent and uninvolved father:

But I say to him that I feel that I’m a single parent, because he comes back and he will even stay on [the] computer until twenty minutes before dinner is ready [she has three young children to watch while making dinner]. He will stay in his room [the computer room]. He won’t be in the kitchen. So, when dinner is served he will come up and eat. After eating, the most he helps me is to do some dishes, half of the dishes, and then he will come down [back to the computer room downstairs] until the time for bed. Yes, and he has no time to talk to me, no time for quality communication time. No, not even at all when he comes upstairs. He already feels tired and likes to watch ten to fifteen minutes of news or television, and then he will go to sleep.

For reasons of space, I will end this quote here, but her graphic story continued by her sharing how she and her partner very seldom have any intimacy anymore, that her partner has these needs met instead on various internet sites in the computer room that he locks himself in for hours at a time. As hard as it is to believe, Ms. Single Mom did not passionately criticize her partner. In fact, she said that she “had no complaints” about doing all of the housework and that she had resigned herself to accepting total childcare
responsibilities [because her partner lacked the patience to deal with Cody and would only make a bad situation worse]. All she asked for, and of course never received, was emotional support from her partner to help energize her to carry on with this unbearable load. She said:

I don’t mind, but I want my husband to pay attention [to me] and spend some good quality time with me. Pay attention and spend some time with me as well, so give me, you know, make me happier. Then [this attention will] give me more energy for the kids. And I feel very tired, not physically, but mentally. I’m very tired. I’m very, very tired mentally. Mentally, this is what I need from him.

In all of these situations, it is clearly implied and sometimes even stated that it is the mother’s role to take care of the child, the house, and the myriad other case-management responsibilities. Ms. Barely Survived shared a story of how when she asked her partner for a break, he replied, “I’m not babysitting for you.” It was interesting, she said, that her partner saw it as babysitting as opposed to parenting. Ms. Barely Survived actually ended up separating from her partner because she felt it would be easier to look after her two children on her own than to also look after her domineering, abdicating, and child-like dependent partner. She said: “No, we didn’t separate over David. We separated over my…. I guess I got to the point where I felt like I had three children and not two. And I wasn’t prepared to handle that any longer.”

Sub-Theme 2B: Mothers Abandoned by Informal Support System

“So, it’s very difficult to understand, and especially when you used to walk your child to school with the other neighbours and their kids, and then they start going ahead of you, and you’re feeling wow, what a let down.”

For the sub-theme mothers abandoned by informal support network, the mothers’
experiences were quite varied and can best be understood from a continuum perspective. The support ranged from positive support for one mother, to minimal support for another mother, to a feeling of abandonment for the other mothers. The mothers felt abandoned by one or more of the following groups of people: extended family members, friends, neighbors, and the community in general.

Ms. Pissed Off actually received positive support from her family, friends, and co-workers. She said [when asked how she gets her personal needs met]:“ What I don’t get within my home, I get from outside my home. And I don’t mean it in a bad way. I mean through my friends, through relationships with co-workers, whatever, and my friends...I get support around things happening with [my autistic daughter] or with really deep feelings.”

However, most of the remaining mothers reported feeling abandoned (though not in those words) and “stabbed in the back” by their informal support network for the sole reason that their friends, neighbors, and some family members “rejected” their child with autism because they couldn’t handle the autistic behaviours. Ms. Single Mom talked at length about being harassed by strangers who judged her a bad mother because of her child’s extreme behaviours in the community. She said: “...in that supermarket and that one I cannot take it either. Many times it happen[ed] [in] that one[ supermarket] , many times, yeah, because she’s autistic.” Ms. Abandoned also talked about feeling “rejected” by her career-focused family members who were never there to support her. In terms of friends, Ms. Abandonment said that her “friends just drifted away” because they did not accept her daughter with autism. Ms. Supermom said she and her family lost most of their friends after they had their child with autism, and that trying to make new friends is very
difficult. She said:

It’s very, very difficult because you try to make friends or you try to include yourself as a family to get along or to go to other people’s houses, whatever, but basically we’re loners now. We used to have quite a few friends, but because they didn’t want to share our son, basically that was it. You know, he’s too weird. He’s too different. Then you lose a lot of people.

She went on to say that not only did she lose all her old friends and had a very hard time making new friends, but that she and her daughter had been ostracized by her neighbors and her child’s classmates. She said:

So, it’s very difficult to understand, and especially when you used to walk your child to school with the other neighbors and their kids and then they start going ahead of you and you’re feeling, wow, what a let down. So you go through a lot of emotional experiences, a lot of roller coaster rides...It’s all a reflection on your child and it comes right back in your face. So it’s a stab in the back. So you have to try getting yourself through that so you can get your child through that too because they’re [the child’s] understanding: “Gee, how come they went ahead of us today?”

In contrast, Ms. Single Mom and Ms. Ignored said that they felt most supported, accepted, and comfortable when they avoided public outings in favour of local special needs and/or autism gatherings. For example, Ms. Single Mom said: “This thing [autism] [is] very upset[ting], very pain[ful], but then [a] happy time when party[ing] with ASBC [the Autism Society of B.C.]. This is your home; and sometimes the [out-of-school daycare] – [those are] the best moment[s] for me. Feel accepted, yes, and right place to be, and fun. They’re public strangers, but feel relaxed there.”

**Sub-Theme 2C: Mothers Abandoned by Formal Support System**

“...maybe my social worker didn’t know that I had that depression. I nearly gave up. I nearly gave up on Rajan...it’s just like I’m a beggar, you know, like what I see in India...you can’t really imagine how [what] it is like and to feel rejected.”
In the sub-theme *mothers abandoned by formal support system* the mothers experienced, in varying degrees, a feeling of having to fight the very system and people who were supposed to be there to provide them support and assistance. For most of the mothers this meant having continually to fight with one or both of two key agencies: the local governmental agency that provides services and supports for families with a child with autism (B. C. Ministry for Children and Family Development) and their local school team (B.C. Ministry of Education).

While Ms. I’m OK experienced some support from the various professionals on her child’s team, she found other professionals, the system and its huge waitlists for various services cold, bureaucratic, and insensitive. She said: “What a difference! There was no caring there at all. And, I mean, surely they could tell that I was kind of worried here, about [her child]. But um, yeah there was, they just, no, you’re on a ten-month waiting list, and that was that.” Ms. Pissed Off’s experiences in dealing with the various helping professions were even more negative. She experienced having constantly to fight to obtain much needed services or just to retain current services. She said, “I always feel that I’m fighting or something, fighting to get this or fighting to get that.” When asked against whom she was fighting, she replied, “the social workers, the school, or well just kind of everything. It just doesn’t seem to end, right. It’s like I’m fighting to get services or to retain them, to keep hanging on to that child care worker or to get him other services that he could have that are out there.” Ms. Abandoned (so named because of her main theme of feeling abandoned by the system) also talked at great length about having to fight for services all of the time –
services that she was made to feel were a privilege, not an entitlement, and that she was lucky to get anything. Because these services were absolutely crucial for her and her child, the uncertainty of not knowing that her child would be cared for once she had gone took a tremendous toll on her. She said:

And it’s the constant meetings and fighting for every small scrap that they throw at you. And being made to feel that, you know, you’re lucky to get that, and it’s a privilege....You have to find out through other parents, well, this is what you can get if you only know how to get it. And it’s almost like if you don’t know the system, you might as well throw in the towel and give your child up because it’s very difficult unless you’re willing to make huge sacrifices [mother now crying]. Um, a huge amount to ask of any two people [parents]...Stability is one of the biggest things in an autistic person’s life. They need things to stay the same. They need [things to stay the same], while our government doesn’t provide that. To think that you’re going to go to your grave not knowing where your child will end up [she is starting to cry even more at this point and had a hard time getting her words out].

Ms. Guilty experienced huge waitlists for services despite her desperate need; moreover, she was made to feel like a beggar by asking for these services. She said:

So the process of knowing it – getting the service, being rejected, being on a waitlist and not being able to take care of yourself. I tried very hard to ask for service and then I waited for two years. I really... maybe my social worker didn’t know that I had that depression. I nearly gave up. I nearly gave up on Rajan [by placing him into ministry residential care]....It’s just like I’m a beggar, you know, like what I see in India...you can’t really imagine how [what] it is like, and to feel rejected, and the rejection means Rajan’s life, and it’s not just you don’t get it [services] – it’s Rajan’s future, and until now I always pray to God that Rajan [goes] first before me, you know, not me first, because who would take care of Rajan in the society that I’m dealing [with] right now. I don’t trust it anymore.

Ms. Supermom’s experience related to the pivotal role that schools play, and how a poor special education teacher can create undue stress in a child and mother’s life and even cause a mother to be blamed for something she had nothing to do with. She said:

School is a big factor in day-to-day stress at times, and who is at school can make a big difference in terms of making or breaking things...If you don’t have understanding school staff, then you’re lost. You can lose, and we did. We lost two whole years of school in that because the teacher could[not] care less. The teacher didn’t want to understand, and did not
understand, and again put the blame back on the parent [by] saying you’re not disciplining your child, where [when] it had nothing to do with that at all.

In summary, in this theme mothers experienced feeling abandoned by the very people and institutions that one would and should expect equal responsibility from – their partners – or at least very considerable support from – family, friends, and “helping” agencies. Yet, almost without exception, mothers experienced just the opposite. Rather than feeling that they were working very closely and cooperatively with partners, family, friends, and “helping” agencies, they were instead completely abandoned and left to bear this incredible burden all on their own. Once abandoned, mothers were forced to become supermoms, taking on this unbelievably heavy role all on their own. The question then becomes, at what personal cost do they do this?

**Theme Three: Burdened ‘Supermoms’**

...We have to be supermoms... and it’s hard. And it is very frustrating because it should be fifty-fifty, and it isn’t, and it should be in this time and age....sometimes we feel like, okay, here we go again, and I may as well put on my cape because I have to fly here and fly there and fly there, you know...One of the teachers told me that I should have a cape and roller blades and the whole nine yards because I was doing everything in a day.

In the last theme I showed how mothers were completely abandoned by all those in their lives who were supposed to be equally participating with them or otherwise supporting them in this unbelievably demanding and draining task of not only caring for a child with autism but at the same time also caring for other children, managing a household, and possibly even working outside of the home. Due to the complete and absolute abdication of key others, mothers were forced to take on the role of supermoms. I will show how this
supermom role leads to great personal sacrifices and hardships, and how it takes a
tremendous toll on mothers emotionally and physically. I will show how this toll is
particularly unbearable for mothers who also work outside of the home.

There are six sub-themes to this supermom theme. Sub-theme 3A is: *Mothers are actually supermoms.* Sub-theme 3B is: *Mothers’ lives change completely and permanently, while fathers’ lives change minimally.* Sub-theme 3C is: *Mothers self-sacrifice to cope.* Sub-theme 3D is: *Mothers are plagued with guilt.* Sub-theme 3E is: *The supermom role takes a huge personal toll, emotionally and physically.* Sub-theme 3F is: "Employed supermoms are particularly burdened."

Before getting into the various sub-themes, given the tendency in the current literature to over-emphasize the negative and burdensome aspects of mothering and to downplay the positive aspects, I will begin by sharing what the mothers told me about their positive experiences as being the primary caregiver for their child with autism.

While two mothers spoke only positively about their relationship with their child with autism and the intense satisfaction they found in their caregiving role, most of the other mothers had mixed and contradictory experiences about their caregiving role, while one mother had an almost exclusively negative experience. Most of the mothers spoke eloquently and sincerely about their love for their child, the satisfaction they get from knowing that they are responsible for the progress their child makes and that their child feels safe, trusted, happy, and loved in their presence. All the mothers expressed an awareness that “this [mothering] was the most important job” in their lives. Ms. Abandoned said, “And he’s brought me incredible joy [she was crying as she said this].
And I wouldn’t trade him for the world.”

Most mothers had mixed, ambivalent, and contradictory experiences. Ms. Barely Survived, for example, while speaking about her relationship with her child with autism, said: “And um, that’s tiring...just fighting to be with her in some ways. Being with her is really difficult sometimes, and I don’t mean that in a negative way. I love her and I’ll always love her to death, but I don’t always like her.”

Ms. Guilty, however, had an almost exclusively negative and frustrating experience as primary caregiver for her child with autism. She said:

To tell you the honest truth, no! Everything is negative. I read through that question, but maybe because I have so much more pain in my experience with Rajan rather than happiness - so, no. But I feel ashamed to feel that cause I love my son, and there are moments when I am happy when he is in a good mood, but when he is in a bad mood....And you always think that I gave so much of my time, and you begin to count all of the work that you’ve done, all of the money that I’ve spent - all came to nothing. That’s why it’s just really frustrating, but we still want him in our mind, but in our heart... We’re his parents, so we have to give him another chance.

Sub-theme 3A: Mothers are Actually ‘Supermoms’

“We’ll [my husband and I] have wars or whatever every once in a while where I just kind of lose it, right. I can’t handle it. I can’t do it. I’m not superwoman! I can’t work full-time. I can’t do everything in the house. I can’t do it all, you know, I just can’t do it. And it just doesn’t seem to have an effect, I guess. And I don’t know how to change that.... It really pisses me off!”

With only one exception, all of the mothers shared story after story about having to deal with and juggle endless tasks, responsibilities, relationships, problems, and appointments. In fact, two of the mothers specifically used a superwoman metaphor to describe their impossible task, the quote above from Ms. Pissed Off being one example.
Ms. Supermom (so named because she explicitly used this metaphor several times to describe her experience) in the following quote, though not mentioning superwoman explicitly, refers to the superhuman powers needed as a primary caregiver for a child with autism. She said, “I think we [mothers] have to be powerful, almighty, strong people all the time and go, go, go because we have to be the sole caregiver of our child.”

While there were numerous stories mothers shared about the often impossible tasks they are asked to take on, I will share just one to show how, in this instance, mothers have to juggle very difficult situations with little, if any, support. Ms. Barely Survived shared the following example of trying to buy the week’s groceries while taking care of her son with autism and doing all of this without a vehicle. She said:

Grocery shopping was mine. Often without a vehicle, because we had one vehicle, which was a commercial vehicle for Anton’s business. So quite often I’d go off with David on a Saturday morning on the bus. Go to the supermarket. Do the week’s shopping. Get a taxi back….and that was our routine for the longest time…Yeah, well that was it. I mean David quite often would be, well, he’d be kicking and screaming and tantrumming. He’d be on the supermarket floor kicking and screaming. I’d have to leave my shopping trolley, go outside, take him inside, walk around, trying to calm him down, trying to get him through it, and then go [and] do the shopping. Get the taxi and come home.

Sub-Theme 3B: Mothers’ Lives Change Completely and Permanently, while Fathers’ Lives Change Minimally

“Always being on call. Constantly. Because if the school can’t handle your child, you are there to get called. So again it goes back to your job. You have no life. This is your life. Your whole experience with your child is your life, you know, and if somebody says oh, tell me about your life, [well], my child is my life. Because you live constantly around him.”
Every mothers’ situation involved the all-consuming role of “mom” based around the many and varied tasks and responsibilities of caring for her child with autism, her other children, and the home, with the fathers in these situations playing only a peripheral role at best in the life of their child/ren and in the activities at home. The mothers in all of these situations had most of their time, energy, thoughts, concerns, and identities tied up with being a mother, with the family and home as her central responsibility. The fathers, on the other hand, were almost exclusively work-and-career focused, much as they had been before the birth of their child with autism. The fathers still maintained their prior leisure activities, their jobs/careers, and their self-centered lifestyle, while the woman suddenly became a “mom”, totally lost her prior autonomous lifestyle, and replaced her future with that of her children. Ms. Guilty said, “...because you are emotionally involved here, physically and mentally, and it drives you crazy, and it’s a total change of your life—lifestyle.” Ms. Abandoned said, “Huge time restraints, huge. Responsibilities that just go on and on. And you think that once you’re over one hurdle that it’s going to get better, but it doesn’t get better.” Ms. Barely Survived said, “It’s a constant thing, constant supervision, and that in itself can be a bit at times draining, but it’s so focused that it’s hard to do other things while you’re doing that...Because David’s very, very active, always moving, never seems to be in one place.” Ms. Supermom said, “You have to be there all the time because you never know what they’re going to do. Like Cody would bang pots and pans over his head. He’d get into my pots and pans drawer.”

Whereas the intensity of constant supervision and huge dependency needs are
limited to the infant and toddler years for a typical child, for a child with autism this lasts for many years, if not a lifetime. Ms. Abandoned said, "...They will not graduate from high school and go to university and get on with their life. It's like there is no closure to one area. Which is hard to deal with, really hard to deal with. It's like having a child at home because you will have Hallowe'en at home until you're nineteen."

Having your child/ren become your life often means sacrificing your own needs to those of your child/family.

Sub-Theme 3C: Mothers Self-Sacrifice to Cope

“But, you know, meeting my need, that is out of the question. Whatever spare time I have is Rajan, Rajan, Rajan. Even if the TV is on, my mind is somewhere else. I am constantly thinking. I don’t read anymore. Not just about Rajan. You are not I don’t say relaxed, so you’re always agitated, worrying.”

All the mothers in this study routinely sacrificed their own needs to those of their child/ren and partner. In fact, given the impossible demands placed on them, they seemed to use self-sacrifice as a means of coping with all of these demands. Only by cutting back on their sleep, by foregoing any leisure time, or by skipping their desperate need for a break were they able to find the time needed to meet everyone else's needs. Each mother shared multiple stories about some very difficult situation where her own needs were being negated for the sake of others. For example, every child in this study had either a formal sleeping disorder or at least difficulties sleeping, yet each time it was the mother who sacrificed her need for sleep for the sake of her partner. For example, Ms. Guilty said: “The baby has to eat, so you have to wake up, and you’re on maternity [leave], so dad has to go to work. He has to have enough sleep. And they always tell me to go to sleep when the baby’s sleeping
for three hours for a nap; and it’s only like thirty minutes, and then when you’re about to fall asleep, the baby wakes up.” Ms. Barely Survived said, “Anton would forget the sleepless aspect of it because he generally didn’t, wasn’t disturbed by it… It took quite a toll.”

If it was not sleep that mothers were sacrificing for the sake of their partners, it was their need for a break that they were sacrificing, particularly at times when their child with autism was in crisis. It was the mothers who were always there, hour after hour, despite being so utterly drained, fatigued, and in desperate need of a break. But, with an absent partner, and being abandoned by key others, with little formal services/assistance, they soldiered on. For example, Ms. Supermom shared a story where her son had just been taken by the R.C.M.P. to B.C. Children’s Hospital’s child adolescent ward (C.A.P.E.S) because he was threatening suicide. While her husband was elsewhere, she was forced for hours on end to try and calm her child down. She talked about how utterly drained she was, but how she thought that as the sole caregiver it was her job to push herself beyond all human limits for the sake of her child (and her husband). She said:

Because I couldn’t handle it at that time. I had had enough, and I think we do that as the sole caregivers. Think we have to because, like I said before, we have to be powerful, almighty, strong people all the time and go, go, go, because we have to be the sole caregiver of our child…Yeah, exactly. I am so drained. But in me [something] is saying, You’re right. You can’t let him see it. You’ve got to be there for him. You’ve got to get through all this.

In fact, all of the mothers reported needing a break but being unable to get it. One mother said that she had been on the waitlist for respite for two years and still had no idea when she would finally get this service. Ms. Abandoned actually was able to get some
minimal respite, but I still quote her here because her statement shows how desperate some mothers were to get a break. She said, “...having daycare for the summer gave me the break that I desperately needed. I couldn’t have withstood a whole summer in sheer hell.” Ms. Abandoned also went on to share how conflicts arise between mother and father about getting time away for a break. She said, “And then it became this big huge time fight. Who could get away the soonest. Because one’s been at work all day but the other has had the children all day. So there’s this huge pressure of ‘I need a break’.”

When directly asked about their personal needs and how these are met in comparison with their partners’ needs, all of the mothers said that while they seldom if ever had time to pursue their own interests and hobbies, their partners still kept up their various leisure activities (e.g. basketball, hockey, movies, computer/internet surfing, soccer, skiing, boating, swimming, watching television, or working on a heritage car). When asked how her personal needs were met, Ms. Barely Survived said, “Well, they weren’t. But I didn’t know what they were at that time other than taking care of David. I think women are the emotional caregivers, I think, and when you have a child with special needs...they’re always going to need you.” When asked how her husband got his personal needs met, she recalled one more aspect of her own personal needs. She said, “Oh, yeah, now I had an aerobics class, which I took in my lunch time three times a week...To keep me sane...Yeah, but as I say, it had to be during my lunch break, because there was no morning or evenings or weekends. It just didn’t happen. So it was a question if I wanted to get my hair cut, I had to make special arrangements, really.”
Sub-Theme 3D: Mothers Consumed with Guilt.

“But sometimes, you know, if your child is not improving, you blame it on yourself... But as a mother the guilt is always there... That’s why I tried A.B.A. (applied behavioural analysis).”

Every mother talked about guilty feelings in one of two ways. Firstly, most of the mothers admitted to feeling somehow partly responsible for their child’s poor development and odd behaviours prior to their child being diagnosed with autism. These same mothers reported a feeling of “relief” once their child was diagnosed. Relief partly because they now knew what they were dealing with and could focus their efforts, research, and treatment more specifically, but mainly relief that nothing they had done had caused this congenital condition in their child.

The other way quite a few of the mothers felt guilty related to their child’s situation or to his negative behaviour. This included feeling guilty about their child’s lack of progress and how they felt they should be doing more to achieve improvements; about the havoc their child’s behaviours (e.g. inappropriate touching or aggression) was causing at the school; about their inability to consistently follow a behavioural intervention program; about how their child’s needs were being neglected; or about having feelings about wanting to place their child with relatives or in formal residential care. Ms. Guilty spoke about how guilt made her feel obligated to try a very intensive, expensive, and trying behavioural program known as A.B.A. or the Lovaas Treatment. She said, “Because you know if you don’t do anything, if you’re not on the go, then you just feel guilty and you are left behind,
and you feel the pressure, so you have to be fast. You don’t think of anything – you just go.” Ms. Guilty also talked at length about her struggle with guilt in wishing to place her child either with her parents in India or in the government’s care. In spite of the guilty feelings she knew would ensue, she said she would place her child if the opportunity arose, but she thought that her relatives would judge her very harshly for doing that – despite her child being extremely difficult and taking a huge personal toll on her. She said, “And then my parents realized that I was going down again [depression], you know, and I have Rajan, and they were asking me to take Rajan to India so that you can move on here [get on with her own life]. Sometimes I’m thinking of that stuff, but I feel guilty.”

Sub-Theme 3E: Supermoms Incredibly Burdened

“I don’t know how I survived. I think, looking back on it, I was running on empty a lot of the time…. I was all-consumed with the whole situation…I mean it can also make you ill from the level of activity involved.”

In addition to experiencing all the burdens already discussed in themes one and two and the ones mentioned so far in theme three, mothers also experience a variety of other very taxing emotional, physical and financial burdens. In theme one, mothers’ expertise was often ignored and dismissed, while at the same time they were sometimes blamed for their child’s autistic behaviours. In theme two, I showed how mothers were responsible for all housework, child-care, and case-management responsibilities, and that their partners were almost completely absent from the scene and had abdicated all of their parental responsibilities. Mothers were often abandoned by their friends, family, and neighbors. In addition, they were completely abandoned by the very support agencies that were supposed
to be there to support the family. This abandonment by key others made the mothers very angry and frustrated. In the earlier sections of this supermom theme, I showed how mothers, because they have been completely abandoned by all key others, have been forced to become supermoms and to take these incredible responsibilities all on themselves; how while their lives had completely changed, their partners lives had only minimally changed; how mothers often sacrificed their own needs for the sake of their child/ren and partners; and how many of them are consumed with guilt. In addition to all these burdens, all but one of the mothers in this study also experienced severe emotional and physical burdens.

All but one mother reported significant emotional and/or physical burdens related to being a supermom. The mothers said they felt one of more of the following conditions or emotions as primary caregivers for a child with autism: “feeling ill from the level of activity”, “drained”, “running on empty”, “overwhelmed”, “defeated”, “afraid”, “resentful”, “angry”, “frustrated.” Ms. Abandoned talked about the burden of always being on call and how this can lead to burn out in mothers. She said, “What it comes down to as a mother and a caregiver is that you are on call twenty-four hours a day, seven days a week, fifty-two weeks a year. I personally feel and have felt for many years that the burnout rate has to be very, very high. We know that the families all split up.” Ms. Guilty talked about the burdens of being “depressed” and sleep-deprived. In this next quote, she talked about how hellish life can be as a caregiver and how angry she was towards her child. She said, “So maybe in seven days [only one day] would be a good day. All six days are like, really like, hell; but close to it [hell], and where you just sometimes take a deep breath [the mother takes a very, very long and deep breath], and you know when a nine-year old kid as big as
you he’s kicking you, you also want to kick him back, and you don’t do that.”

Sub-Theme 3F: Employed Supermoms Particularly Burdened

“It’s just a matter of having to keep everything calm. And as hard a toll as that is, if you have to go out and make a living and keep everything on an even keel at home, it is very difficult. It’s very, very draining physically, emotionally, and financially. And that’s I think the biggest thing.”

While working outside of the home had definite advantages, it also had very clear negative implications for the mothers. One of the advantages was that it allowed mothers a chance to take a break from the much more demanding and all-consuming role of being “mom” and just be themselves. Ms. Supermom said, “So that’s why I’m just working at this funny place, even though the pay is really crappy. Anyway, that’s okay, because I need to get out and I need to talk to people, so I can do that. I can go out and be myself and be who I am and not be a mom... I can be me. So that’s why I keep my job.”

As already shown, the mothers were forced to become supermoms, but at a huge personal cost. Yet, being an employed supermom was even more burdensome. Instead of participating more fully and equally in all of the many housework, child-care, and case-management responsibilities because of the mother becoming employed, the fathers, as already shown, took on very little, if any, extra responsibility in those areas. Instead, the mothers continued to have total responsibility in all of those areas while still working outside of the home. For example, Ms. Guilty, who worked part-time, mentioned how working was not the break that her parents told her it would be. She worked the morning shift as a kitchen helper, which meant that she had to be up at 5:30 in the morning, despite
not getting much sleep that night because her child was regularly up at night. She then had to rush home to pick her child up from pre-school. What her employment meant, she said, “was another load of work” on top of everything that she was already doing at home. Ms. Supermom, who worked close to full-time hours, talked about how depressing a life she had. She said:

…and you know I went through a depression two times...of being down in the dumps and yelling and screaming at the whole world, and, you know, letting the world know that you’re mad as hell...I was down in the dumps. Couldn’t stop crying. I cried and cried and cried. I felt sorry for myself. Why did this happen to me type [of] thing, putting it all back on me again? Like all the guilt, all the blame, went all back on myself again. Went to the doctors, got medicine. That didn’t work because I learned it was the same stuff that Simon took.

Lastly, five of the six mothers who worked outside of the home and yet continued to be responsible for all housework, child-care, and case-management tasks, spoke about feeling resentment towards their partner for this unfair and grossly inequitable burden. With the exception of one part-time employed mother, all of the other working mothers spoke of being “resentful”, “bitter”, “angry” or “very angry”, “frustrated”, “hurt”, “bothered”, and/or “pissed off” with their partner because of the unequal distribution of work. Ms. Guilty said, “Everything that happens with Rajan is with me. During that time I was really angry because I was feeling the rejection and all of that...you just can’t do it. There came a point, too, that we had competition [about] who does so much and who does less, da, da, da, da. And then he feels ashamed because I also do this, I also do that....resentment because your life is on hold. Everything is Rajan, Rajan, Rajan, Rajan, Rajan. “
Only when directly asked to put their situation into the context of other women’s situation in general did the employed mothers (with the exception of one mother) speak about how women are treated unfairly by men in general, that women are simply “expected to be the sole-caregiver”, and that “women are naturally the emotional caregivers”. For example, Ms. Pissed Off said, “I think it’s been going on for many, many years, right. I mean like 60 years ago, women didn’t work, women were shit right, women weren’t anything, and so it’s kind of been a whole progression, and I think eventually it will get there, but it’s just [that] I think more women need to feel empowered [so] that they can stand up to that, including myself, that it’s okay to take a stand, and stay there and not to back down.”
CHAPTER 4 DISCUSSION

There were two main insights that emerged from this study. The first is that it is not
the mothers' experience with their child with autism that is central to their experience but
rather the relationship, often negative, with their support system that is key to the
experiences of caring for their child with autism. Prior to each interview I told the mother
that she was the expert, not me, about her own experience caring for her child with autism
and that only she knew and felt what issues, stories, incidents, experiences, feelings etc
were fundamental to the essence of her overall experience. In each interview the first
question asked was "Please share with me, in as much detail as you can, what your
experience, as primary caregiver, has been caring for [name of child with autism]. Each
mother then spent at least one hour or more answering, often very emotionally, this very
broad and open-ended question focused on her caring experience directly with her child
with autism. Only later in the interviews did I asked specific questions about the
differences between the mothers and fathers' experience caring for their child with autism.
Yet, in the end the mothers did not focus on the relationship with their child with autism or
the caring work involved. Rather, they focused on their relationship, often negative and
unsupportive, with key others, such as their partners, the "helping" professionals, family,
and friends. This suggests that it is not the caring for the child with autism that is central to
the mothers' experience but rather the relationships with other adults/support systems
around her. Both themes one and two speak to this aspect of their experience. Theme one
focuses on how their partners and family doctors ignored the mothers' concerns about the
early signs of autism and how other key professionals, such as teachers, psychiatrists,
behavioural consultants, and group home workers, ignored the mothers’ expertise about how to manage their child’s autistic behaviours. Theme two focuses on how these mothers were completely abandoned by all those key people around them that either should have been equally involved, such as their partners, or at least significantly supporting them in this caring work, such as their informal support system of family, friends and neighbors, and their formal support system of the various helping professionals, such as social workers and teachers. All but one mother felt completely abandoned in at least two areas of her support system. The other mother felt abandoned in only one area of her support system.

The second main insight is that since mothers of children with autism are completely abandoned by key others they are forced to become ‘supermoms’ who take on an unbearable workload, but at huge personal cost to their physical and emotional well being. The third theme focuses on the mothers’ experience of sheer survival in this impossible role of supermom and the terrible toll it takes on them. This was the experience of seven of the eight mothers. The other mother did not feel terribly burdened.

In this chapter I will discuss my conclusions about the three themes that I have developed; relate the themes to the current literature; and discuss the implications of these themes for social work practice and policy. Lastly, I will discuss the limitations of my study as well as suggest areas to focus on for future research. For reasons of space, I will focus my conclusions, relation to literature, and practice and policy implications to just the key findings of each theme overall and not to each sub-theme of the three themes.
THEME ONE: IGNORED

Conclusions

In terms of theme one all eight mothers clearly demonstrated, in a variety of ways, that they were the most knowledgeable people about their child's needs, strengths, personality, and about what works and what does not work in the management of their child's behaviour. While professionals came and went, the mothers remained as the primary caregivers and intensely involved in the care of their child over a very long period. With such intense involvement came a high degree of expertise about both their child's needs and how general interventions proposed by the various professionals may or may not work or how these interventions needed to be adapted to best work with their child's very unique autistic behavioural profile. For example, both the partners and especially the various family physicians kept ignoring, dismissing, or even blaming the mother regarding their concerns about the early signs of autism in their child. The partners or physicians told many of these mothers that they were simply over-reacting, worrying about nothing, that everything would be fine, etc. Yet, in each case, the child was eventually diagnosed with autism, confirming that the mother was not over-reacting at all, and that in fact she identified the problem long before the professionals or partners did.

Relation to Literature

Unfortunately, the experience of these mothers of being ignored and dismissed by professionals is consistent with the current literature about the experiences of most typical mothers. As mentioned in chapter one, once mothers are assigned the responsibility of
caring work, this work then becomes undervalued, invisible, unacknowledged, ignored, and/or even treated with contempt (Baines, Evans, Neysmith, 1998, p.4; Brown et al, 1994, p. 161 & 202; Fellman, 1990, p. 229; Ferguson, 1998, p. 197-200; Fineman, 1999, p. 149; Fox, 1997, p. 153; Gerson, Alpert, & Richardson, 1990, p. 32; Nedelsky, 1999, p. 321; & Rossiter, 1988, p. 97 & p. 277); disempowered and disregarded (O'Barr, Pope, & Wyer, 1990, p. 2); or only noticed when it does not get done (Brown et al, 1994, p.202). Mothers are on the one hand ignored and considered lacking expertise, yet on the other hand are held responsible for all failures. Rossiter writes: “We can clearly see the double bind which applies to mothers: mothers are invisible and inexpert; but, though they are powerless, they are at the same time responsible for all failures (1988, p. 175).” Specifically, this matter of mothers being ignored and dismissed by physicians or pediatricians when trying to get a diagnosis for their autistic child is consistent with the literature (Waltz, 1999, p. 41).

Policy and Practice Implications

In terms of the sub-theme that mothers' concerns are only heard when corroborated by others, social workers could suggest to mothers videotape their child's bizarre behaviour when it is occurring so that they can go into the pediatrician's office armed with evidence of their concerns about their child's development. One mother of an autistic child wrote: “And now here I was, feeling walked away from, minimized. In the months that followed, I wish I'd thought, or been told, to videotape my daughter's screaming or to turn on an audiotape recorder....Finally, I was heard. Finally, I was believed (Marsh, 1995, pp. 21-22).” Another option that social workers could suggest to mothers is to set a “wait and see”
timetable with their child’s physician. Such a timetable involves the parent(s) and physician being clear about what developmental milestones should be achieved within the next three months, and then agreeing that, if these are not achieved, the physician will then make the appropriate referral (Waltz, 1999, p. 41).

Social workers need to play a central role in facilitating the development of support groups for mothers more widely in order to tap into this expertise that mothers have in a variety of areas, such as behavioral management expertise, sharing their own experiences, and knowledge of local resources and services (Lerner, 1998, p. 50 & Waltz, 1999, p. 195). Frequently, it is these types of informal support services, often developed by social workers, that have the most positive impact for mothers, even more so than formal support services (Waltz, 1999, p. 377-381). As one mother of a special needs child wrote about seeing a past mother from her old support group whom she had not seen in five years: “I’m telling you, the gut stuff that comes out in two minutes because of what you’ve been through...I mean, that relationship automatically comes back. It’s like you are war veterans. It was just amazing (Marsh, 1995, pp. 43-44).”

THEME TWO: ABANDONED

Conclusions

In terms of theme number two all but one mother spoke about their frustration in at least two of the three sub-theme areas: (1) being completely abandoned by their partners in terms of assisting them with housework, child care and case-management tasks; (2) being abandoned by their family, friends, neighbors, or community; and (3) being stranded alone, without much, if any, formal support services, or support from other key professionals. The
other mother only felt abandoned in one sub-theme area.

As already discussed in the introduction to this chapter, this experience of lack of support from their support system was central to their overall experience of caring for their child with autism. It was not the mothers’ relationship with their child with autism that was key but rather their relationship and involvement, or lack of, with key adults in their support system that was central to their experience.

**Relation to Literature**

Other mothers of special needs children have consistently reported feeling abandoned by their informal support network of families (Waltz, 1999, p. 375), neighbours (The Beresford Report, 1995, as cited in Read, 2000, p.59; & Waltz, 1999, p. 384), friends (Waltz, 1999, p. 375), and the community as a whole (The Beresford Report, 1995, as cited in Read, 2000, p.58; Marsh, 1995, pp. 82-83; & Waltz, 1999, p. 333).

The experience of the mothers in this study is consistent with the reality for mothers in general of being abandoned by their partners. In terms of housework, as reported in chapter one, typical fathers do only a “measly 2 hours more of housework” - up to a total of 13 hours per week - when compared to the 11 hours per week they did three decades ago (Maushart, 2000, p.185). Only one-fifth of fathers are “fully involved” in sharing housework responsibilities (Maushart, 2000, p.186). Near the other end of the continuum, only about one-fifth of fathers even “help out” with household chores (Gordon, 1990). Mitchell (1996), as reported in Maushart (2000, p. 186), concluded that, out of the five household chores examined, men routinely did only one – household repairs.
All the mothers in this study had absolute responsibility for all child-care. This is so for most ‘typical’ mothers, as reported in the literature (Brown et al, 1994, p. 163 & 211; Forna, 1998, p. 226; & Maushart, 2000, p. 225) as well as mothers of a child with special needs (Marsh, 1995, pp. 103-124) or autism (Waltz, 1999, p. 324).

In terms of the mothers experience of being abandoned by their formal support system, this too is consistent with the literature which documents the very long waitlists for services for families with a child with autism in both Canada and the U.S. (Waltz, 1999, p. 44 & p. 49). Families caring for a child with special needs have been enduring very long waitlists for services such as respite, behavioural consultation, life skills workers, and day programs (Seligman & Darling, 1997, p. 83). Yet, Seligman and Darling go on to argue, it is the provision of these formal support services for parents of a child with special needs that more than anything else (including parental competence or level of acceptance) determines how well a family adapts to their situation (Seligman & Darling, 1997, p. 79).

**Policy and Practice Implications**

Parental leave should include additional leave options just for fathers. Such a policy would encourage fathers to bond more meaningfully with their children and help them become a more competent and committed parent. Such a policy would also lead fathers to a greater appreciation and a deeper understanding of the sheer hard work involved in being the primary caregiver. (Brown et al, 1994, p. 222). Even if many fathers did not take a formal parental leave, just ensuring that fathers are left alone with their child(ren) as often as possible, without the mother’s supervision, expertise, or advice, would go a long
way in letting fathers learn to be more competent and committed (Lerner, 1998, p. 41).
Mothers must also begin demanding an end to absent and uninvolved fathers and to not feel guilty about this or feel that she is being a nag. Rossiter writes: “When one of the ways of taking care of myself is to demand participation in caretaking from their father, I must stifle the voice that says “bitch, nag” and instead congratulate myself on my contribution to fully human fatherhood (1988, pp. 279-280).”

THEME THREE: BURDENED ‘SUPERMOMS’

Conclusions

In the last theme I showed how mothers were completely abandoned by all of those in their lives who were supposed either to be equally participating with them or fully supporting them in the unbelievably demanding and draining task of simultaneously caring for a child with autism, managing a household, possibly caring for other children, or possibly even also working outside of the home. As a result of the complete and absolute abdication of these key others, mothers were forced to take on the role of supermoms.

The burdens these mothers experienced were significantly compounded if any of the following conditions applied: the mothers also worked outside of the home; their child’s autism was severe; the child had additional disabilities, such as a seizure disorder, ADHD, or sleeping disorder; the mother was exposed to other significant stressors, such as having to care for other children; or the mother received only minimal and inconsistent support from her partner, her informal support network, or her formal support network.

Ms. I’m OK was the only mother who claimed that said she did not experience any
significant burden and who was adamant that she did not suffer any emotional and physical harm. She did not work outside of the home; her child’s autism was only mild to moderate; her child did not have any additional disabilities, such as a sleep disorder; she only had one child; she claimed that she was supported by her partner; she did not experience any change in the amount and kind of support she received from her informal support system compared to the support she received prior to having her child; and she had less need for formal support services.

At the other end of the continuum was Ms. Barely Survived. She experienced the harshest burdens since she also faced all of the additional compounding conditions. She worked full-time outside of the home; her child’s autism was profound (e.g. non-verbal, severe self-injurious behaviours like head-banging to the point of getting black eyes); her child had additional disabilities (a profound mental handicap that left him totally dependent for all toileting, bathing, dressing, and eating, ADHD, and a severe sleeping disorder); she had one other very high needs child whose needs she constantly struggled to try and meet; she was absolutely abandoned by her partner who did no housework, childcare, or case-management tasks; and she was abandoned by both her informal and formal support systems.

These findings lead towards developing an evolving insight into the day-to-day reality of mothers as tremendously burdened primary caregivers for their child with autism – especially if they also work outside the home; and how such a tremendous burden is grossly unfair and impossible to endure long term without significant physical exhaustion and/or emotional harm.
Relation to Literature

Without exception, all of the mothers in this study experienced a profound and permanent change in their lifestyle and identity, while their partners experienced extremely little, if any, change in their lifestyle. This is very consistent with the literature (Brown et al, 1994, p. 162; Forna, 2000, p. 220; Fox, 1997, pp. 143-145; & Lerner, 1998, p. 53).

This change of lifestyle, however, is much more long-term for mothers caring for a child with special needs than it is for typical mothers (Waltz, 1999, p. 83). Whereas many "typical" mothers can slowly begin to have more distance from their child once the child sleeps through the night, can independently go to the washroom, bathe him/herself, dress him/herself, and eat independently, this is not always the case for mothers of a child with special needs or autism. Mothers of a child with a disability often "arrange their whole lives around the caring work and the child" because of the constant and severe needs of many of these children. Some of these needs require mothers to "constantly supervise" their child, to be up most of the night with their child with a sleeping disorder, "to constantly fight for services," and to coordinate many different professionals on their child's team (Traustadottir, 1991, p. 221).

Without exception all of the mothers in this study routinely negated their own needs for the sake of others in the family, including (although to a lesser extent) the two stay at home mothers. The mothers in this study consistently sacrificed their need for sleep, their need for a break, and their need to pursue their leisure activities, etc. They did this partly because the expectations and demands on them were so great and impossible to meet that
unless they saved time by negating their own needs, they would have had no chance of fulfilling all of these expectations. Tragically, this finding is very consistent with the current literature. The good mother is the all-sacrificing mother (Cooper, 1999, p. 270; DiQuinzio, 1999, p. xiii; Fellman, 1990, p. 228; Forna, 1998, p. 3; & Fox, 1997, p. 155).

Most of the mothers felt considerable guilt, and two mothers in particular were consumed by it. For example, Ms. Guilty was guilt-ridden about giving birth to an autistic son; about having her child go to live with her grandparents in India; about placing her son in government residential care; and about feeling that other parents were doing more for their child with autism, so why was she not able to do the same. Ms. Guilty was very clear that the only reason why she spent so much energy, time, and money trying to implement an A.B.A. program for her son was because she felt guilty about giving birth to a child with autism. Unfortunately, this finding that guilt is a common, powerful, and motivating factor in mothers' lives is consistent with the current literature (Forna, 1998, p. 12; Lerner, 1998, p. 75; & Rossiter, 1988, p. 137). Guilt can be particularly painful and powerful for mothers of a child with autism (Waltz, 1999, p. 81). Professionals sometimes expect mothers to follow-through on complex, time-consuming, and unrealistic interventions; and this can generate considerable guilt in mothers of special needs children if they are not able to live up to these impossible standards (Kittay, 1999, p. 22).

Only one of the eight mothers did not report any significant emotional and/or physical burdens as a result of being a supermom. Tragically, once again these horrific findings about how burdened mothers are is consistent with the current literature. Mothers experience a variety of negative emotions and conditions, particularly new mothers and
mothers with young children (Brown et al, 1994, p. 173; Cooey, 1999, p. 238; Forna, 1998, p. 12; Fox, 1997, p. 153 & p. 144; & Gerson, Alpert, & Richardson, 1990, p. 25; Lerner, 1998, p. 45; Maushart, 2000, p. 121; O’ Barr, Pope, & Wyer, 1990, p. 5; & Oakley, 1990, p. 70). As burdened as these ‘typical’ mothers are, mothers caring for a child with special needs are often consumed by the intensity and permanency of the caregiving work – while many mothers of ‘typical’ children tend to mainly experience this intensity only while their children are very young (Kittay, 1999, p. 11 & p. 17; Marsh, 1995, p. x; Read, 2000, pp. 21-26 & p. 54; & Seligman & Darling, 1997, p.96). Other studies have found that parents of a child with special needs whose main issues are behavioural, such as autism, face considerably more stress than do parents of a child with special needs whose main issues are physical in nature, such as spina bifida and cerebral palsy (Konstantareas, 1991; & Seligman & Darling, 1997, p. 107). Parents of a child with autism in particular face great challenges in treating the condition and/or “tolerating” the constant behavioural issues (Seligman & Darling, 1997, p. 111). Mothers of child with autism often feel resentment due to lack of free time, undisturbed sleep, and isolation, among other reasons (Waltz, 1999, p. 326).

Consistent with the literature on employed mothers, the employed mothers in this study experienced very significant burdens trying to balance their home and work responsibilities. The problem is that in addition to working full-time outside of the home, they are still burdened with nearly all of the household chores and childcare responsibilities – a full-time job in itself (Ferguson, 1998, p. 198; Forna, 1998, p. 226; George, 1998, p. 76; & Luxton & Reiter, 1997, p. 198 & 205). This burden is the same for mothers of a child
with a disability (Traustadottir, 1991, pp. 221-225).

So, all of the themes and sub-themes are very consistent with the current feminist literature on motherhood in general and with the literature on mothers caring for a child with special needs and/or autism. The only difference appears to be that mothers caring for a child with autism, particularly the employed mothers, experienced these many different hardships and burdens more intensely and for a much longer period of time than do typical mothers.

**Policy and Practice Implications**

The destructive patriarchal notion of motherhood that expects nothing less than perfection and an all-sacrificing mother will not change until the children of today are proactively given different role models and gender expectations to witness and experience. The patriarchal norms that teach girls that it is their role to be society’s carers and to neglect their own needs in this process are some of the first things that must change. They can change by allowing girls safe opportunities to ‘resist’ the daily ‘policing’ of their feminine behaviours and attitudes. Girl Guides, which works exclusively with ten per cent of Canada’s young girls and which is re-affirming its commitment to pro-female principles, is well positioned to take this leadership role (Reitsma-Street, 1998, p. 106), as are the schools (Reitsma-Street, 1998, p. 106). Olafsdottir (1996 as cited in Reitsma-Street, 1998, p. 106-107) argues that systemic alternatives are needed in caring lessons by age five. If the Canadian child-care system was designed to encourage men to become more actively involved in parenting, then “both boys and girls could see a broader range of role models, thus expanding the life choices of all children (Ferguson, 1998, p. 207).” Absent,
uninvolved, and abdicating fathers teach girls that this "is a prediction of the responsibilities they may expect when they become mothers; for boys, this picture provides a script for avoiding responsibility in the future (Swift, 1998, p. 181)."

**Summary**

This exploratory qualitative study into the experiences mothers of a child with autism have with their support system provided some beginning insight into how completely ignored and abandoned these mothers were by those who were supposed either to equally share the parenting role or to fully support her. It was not the caring for their child with autism that was most central to their experience but rather their relationship, often negative and unsupportive, from those in their support system that was most crucial in how they perceived their experience. Left on their own, these mothers were forced to become 'supermoms'. This supermom role took a huge physical and emotional toll on these mothers, particularly on the employed mothers.

**LIMITATIONS OF STUDY AND RECOMMENDATIONS FOR FUTURE RESEARCH**

There are two key limitations to this study. The first gap is that this study, like the current literature, for the most part ignored the experience of non-white mothers. To date, the vast majority of feminist research into motherhood has focused exclusively on Western mothers and has excluded the experiences of mothers from other cultures. The second limitation of this study is that, like the current literature, it ignored the experiences of fathers (Forna, 1998, p. 241; Read, 2000, p. 3). I relied on what mothers told me about the role, or lack of a meaningful one, that the fathers played in parenthood. I also relied upon
them to describe what feelings the fathers had about this role or about how to change this unfair situation.

This being the case, future research should focus on the experiences of mothers from a particular ethnic background in Canada. As part of this study, the fathers should also be interviewed to better understand the differences in experiences between mothers and fathers.
APPENDIX A: INFORMED CONSENT FORM

A FEMINIST ANALYSIS OF MOTHERHOOD: THE EXPERIENCES OF MOTHERS CARING FOR A CHILD WITH AUTISM

Principal Investigator: Dr. Marg Wright
Co-Investigator: Rayner Sutherland

WHO IS DOING THE RESEARCH AND WHY?

My name is Rayner Sutherland and I am a Masters of Social Work (MSW) student at the University of British Columbia, School of Social Work and Family Studies. As part of my MSW thesis I am conducting a qualitative research study about the experiences of mothers caring for their child with autism.

While there is considerable research available about the impact on families of having a child with special needs, there is very limited information about the actual experiences (i.e. thoughts, feelings, beliefs, etc.) of parents, related in their own words, of caring for a child with special needs. There is even less research available of the different roles and experiences of mothers and fathers in caring for their child with special needs. There is extremely limited research available, focusing specifically on autism, from the parent’s perspective, about their experiences of caring for their child with autism. To the best of my knowledge, there has never been a qualitative research study that specifically focuses on the experiences of mothers, as primary caregivers, for their child with autism and the unique and key role they play in their child’s life.

WHAT IS INVOLVED?

I will be interviewing a number of mothers of a child with autism. Each interview will be taped and later transcribed. From these transcripts a qualitative analysis will be done comparing the experiences of each mother and looking for differences, similarities, and patterns. Eventually, I will end up with a core set of themes that describe the experiences of mothers caring for a child with autism.

There will be two interviews, both of which will happen at a time a place of your choosing. Each interview will take between one to two hours. After I have interviewed all of the mothers, I will interview you a second time to share with you the tentative themes that I have identified and to get your expert feedback on whether or not these themes reflect your understanding of your situation. If these themes do not accurately reflect your reality, then I will change the themes accordingly.
APPENDIX B: LETTER OF INVITATION

A FEMINIST ANALYSIS OF MOTHERHOOD: THE EXPERIENCES OF MOTHERS CARING FOR A CHILD WITH AUTISM

Principal Investigator: Dr. Marg Wright
Co-Investigator: Rayner Sutherland

LETTER OF CONSENT

This form provides you with the information you need before deciding if you are going to participate in this research study. As you know, I am conducting this study about the experiences of mothers caring for their child with autism as part of my Masters of Social Work thesis.

Purpose of Study

While there is considerable research available about the impact on families of having a child with special needs, there is very limited information about the actual experiences (i.e. thoughts, feelings, beliefs, etc.) of parents, related in their own words, about caring for a child with special needs. There is even less research available of the different roles and experiences of mothers and fathers in caring for their child with special needs. There is extremely limited research available, focusing specifically on autism, from the parent’s perspective, about their experiences of caring for their child with autism. To the best of my knowledge, there has never been a qualitative research study that specifically focuses on the experiences of mothers, as primary caregivers, for their child with autism and the unique and key role they play in their child’s life.

What is Involved?

I will be interviewing a number of different mothers of a child with autism. Each interview will be taped and later transcribed. From these transcripts a qualitative analysis will be done comparing the experiences of each mother and looking for differences, similarities, and patterns. Eventually, I will end up with a core set of themes that describe the experiences of mothers caring for a child with autism.
Consents:

I understand that my participation in this study is entirely voluntary and that I may refuse to participate or withdraw from the study at any time. I also acknowledge that I have received a copy of this consent form for my records.

I consent to participate in this study.

Signature of participant: ______________________  Date: ______________________

Signature of Witness: _______________________  Date: _______________________
BIBLIOGRAPHY


Luxton, M., & Reiter, E. (1997). Double, double, toil and trouble...women’s experiences of work and family in Canada. In P. Evans, & G. Wekerle (Eds.), *Women and the Canadian welfare state: Challenges and change* (pp.197-221). Toronto: University of Toronto Press.


