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Daughters of mothers with Multiple Sclerosis: Their experiences of play

by

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For: Heather

A woman who is my unending inspiration of strength and courage.

ABSTRACT

This study described the play experiences of daughters who were caregivers to their mothers with multiple sclerosis (MS). The experiences of four Canadian-Caucasian women aged 19-26 were captured using phenomenological methods of individual and focus group interviews, field notes, and artefacts. Three themes with supporting sub-themes emerged: (a) being a good daughter, (b) blurred relationship boundaries, and (c) encumbered play. Caregiving for their mothers was part of being a good daughter. Excessive caring duties changed their roles from being daughters to caregivers and contributed to feelings of maturity over peers. Their mother-daughter relationship boundaries were blurred and the participants wished to spend more time as daughters. Play, although sometimes limited, was highly valued and provided an escape from caregiving. Using family systems theory to interpret the findings, it was concluded that support for families living with MS would release children from caregiving duties so rounded childhood play could be experienced.

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1. INTRODUCTION

I discovered the power of play in the summer of 2006 when I was a participant in the program Play Around the World (PAW). PAW is an academic offering designed to provide a global education cross-cultural experience to its participants. Multidisciplinary teams of senior undergraduate and graduate students form learning communities who work with agencies in Thailand that care for under-served populations (e.g., children who are orphaned or abandoned, and people of all ages with disabilities or HIV/AIDS). PAW sends 8-10 university students for three months to share the benefits of play and recreation with these underserved populations. The PAW program seeks to broaden the world view of its participants through a cross-cultural placement in which students use their educational and experiential backgrounds in play and recreation to enliven the human spirit and optimize the development of those who, for a variety of reasons, are less able to access and receive these benefits. In the process, students further their abilities to engage others in play activities, in an environment which is challenging due to the language, culture, and abilities of the children. The students spend the months from January to April preparing for their placements. This preparation involved attendance at weekly preparatory meetings, fundraising, team-building, and a weekend retreat. The weekly two and a half hour meetings focused on many different aspects of preparing to volunteer internationally.

When I was a PAW participant, ten university students were selected, and I and four others completed our placements in Pattaya, a city located two hours southeast of Bangkok. The other five selected students were placed in Chiang

Mai, a city located in the North of Thailand. While we learned a bit of Thai language, most communication was non-verbal. The connections that were made with the children were very strong and palpable, and were mostly facilitated through the universal language of play. My experiences with PAW helped me to realise the power of play. I will exemplify this last statement with the story of my friend Gip.

* * *

As our song tao¹ pulled up to Baan Jing Jai, a shelter in Pattaya, Thailand, I felt nervous about visiting a “Thai-run” organization. All the introductory meetings up to this point were with primarily Canadian or European ex-pats who ran the organizations of our potential placements and communication was a non-issue...until now. We stepped out of the song tao in the 40°C weather, *tried* to tell the driver what time we needed to be picked up, and my four team mates (the other university students placed in the same city as me) and I walked along the dusty road to what would become my favourite of the five volunteer projects that summer.

As we entered the yard, nearly 50 pairs of brown eyes belonging to curious children gazed in wonder at the five pasty white university students who had just shown up to their home. I felt their eyes were saying, “*What are they doing here? Have they come to bring a treat?*” We looked around, trying to find out who was “in-charge”, and smiled nervously at the awe-struck children and attempted to say hello in botched Thai.

¹ A song tao is a type of truck that is used often as a taxi in Thailand.

“*Sawasdee ka*²”. We waived, equivalent to our handshake in North America, where you nod your head, bow, and place your hands in prayer position. I thought to myself, “*what are we doing here? How can we have an impact when there’s so many of them? How will we communicate with them? Do we belong here?*”

Carrie, one of my teammates, spotted five women sitting on the concrete picnic-like table in the corner, and we made our way over to speak to them...or at least try. We struggled through our meeting as it was difficult to convey why we were there and what we hoped to do. At the same time, however, they were very easy going and didn’t seem to mind that we came or what we did. I wondered, “*was that the Thai way, or was it a reflection of the language barrier?*” We said to the lady who ran Baan Jing Jai:

“*We are from Canada and would like to play with the children*”

“*OK, it’s OK...*” she replied.

“*We can come then?*”

“*Yes, you come play with children.*”

Shortly after this exchange, our driver arrived, half an hour early; we tried to tell him to come at 6:45, but it turned out we told him 6:15—so much for trying to speak Thai! In any case, we left our first visit to Baan Jing Jai with plans to return the following week and play regularly on Tuesday, Thursday, and Friday after the children were out of school.

* * *

A few days later we returned to Baan Jing Jai. As our song tao pulled up to

² “Sawasdee ka” means “hello” in Thai.

the shelter for the second time, I was still nervous. *Will they like us? Do they get why we're here? Will they have fun?*" We negotiated our pick-up time with Moo, our driver, grabbed our big bag of equipment and stepped once again onto the dusty road that bordered their home. Some children came over to greet us, still with that puzzled look in their eyes, while others stayed where they were, choosing to hesitantly observe from afar. As soon as they realized what was in the bag, almost every child who was there darted toward us. Every child but one. They created a melee of mostly Thai children, mixed with a few taller Canadians (i.e., my team mates and I), all vying for the fluorescent nerf football, one of the soccer balls that we brought over from Canada, or whatever else they could get their tiny hands on, including bracelet making supplies and facepaint. After the huddle broke and the majority of the children were playing with their chosen piece of equipment, I noticed there was a little girl crying as she swung on the swing set. I walked over to see what was wrong.

"Are you OK?" Nothing. She probably doesn't understand.

"Does anyone speak English?" I asked some of the children around us,

"What's the matter with her?" They shrugged their shoulders.

Either they didn't understand or they also didn't know what the matter was.

I decided to try and cheer her up. *Maybe she wants to play with some of the equipment we brought?* But she wasn't interested. So I just sat with her on the swings. I held her and I sang to her. She sulked the whole two hours we were there (maybe it was my singing?), despite my best efforts to cheer her up.

Thursday and Friday rolled around and still this child, Gip, was sad; mostly

keeping to herself in the corner, not wanting to play with anything or with anyone. I was persistent—I kept trying to involve her in the activities and I simply held her. I wanted her to know that I cared. My persistence paid off. After a few visits, she slowly began to participate in the activities. Soon enough, Gip, along with the other children, would run up to our song tao as soon as it arrived (before Moo could even stop!) so they could see what fun things we brought for them to play with that day. We tried to hold them off from taking the bag full of balls of various sizes and colours, a parachute, jacks, art projects, skipping ropes, hula hoops, and sand toys out of our hands until we were at least out of the vehicle, but alas with little success!

Gip and I would play together every Tuesday, Thursday, and Friday, and after a while, her trust in me began to grow, as did her smiles. The memory I have etched in my mind, and hope to never forget, is when we were driving away from Baan Jing Jai at the end of our last day. Some children were crying (as was I!) and some were smiling; all of them chased after the truck waving goodbye, saying I love you (both in Thai and English), and thanking us for coming to play. The last face I saw was Gip's, smiling ear-to-ear, waving goodbye; we made eye contact as she stood there in her red shirt and bare feet. Those brown eyes were no longer curious or sad, there was only happiness. I wonder if I would have ever seen that lovely wide smile that framed her in-coming two front teeth, stretched from ear-to-ear if it hadn't been for play. How would I have shown Gip that I cared if it weren't for the universal language of play? Play allowed me to realize the resiliency in children. I believe that all children possess this quality and, if

given the opportunity, let it shine through.

Illustration 1. Girl captured at the beginning and the end of the Play Around the World Program



Curiosity before judgment – it’s a phrase I learned as part of my preparations to go to Thailand with PAW and it remains as one of the mottos I live by. Essentially it invites you to ask *why* something (or someone) is the way it is before passing judgment. Being willing to ask the question may bring understanding to the situation. This phrase led me to the inspiration for my master’s thesis topic.

One of my PAW team mates, Colleen³, was self-admittedly not athletic. After jokingly making fun of her for not being able to catch a Frisbee or having an awkward running gait, “curiosity before judgement” provoked me to stop and I asked her why she perceived herself to not have much athleticism. She quickly knew the answer. This conversation was so pivotal for me that it was one of those moments where I remember exactly where I was when it occurred. I can still

³ Pseudonyms were utilized to protect the anonymity of all people mentioned in this manuscript.

visualize the exchange vividly.

Growing up Colleen was her mom's caregiver and had few opportunities to participate in spontaneous play, physical education (due to absences and subsequent avoidance), or after school sports teams. Her mom has multiple sclerosis (MS). Colleen's parents divorced when she was very young. As a result, Colleen became her mom's primary caregiver, which she said contributed to fewer opportunities to experience play and physical activity than her peers. She told of having to care for her mom, do the laundry, or cook supper, which all took precedence over playing at a friend's house, or attending volleyball practice. After hearing her story, I wondered if other girls who have moms with MS also experienced restricted play and physical activity opportunities, which brought me to the topic of my research.

Children may assume caregiver roles when one of their parents has a disability, particularly in instances when there is little or no extended family (Aldridge, 2006). Having no extended family can influence the nature and frequency of tasks that young carers undertake and may prolong the duration the child is relied upon for support (Aldridge & Becker, 1999). If there is no other adult present in the home, for example, a child is more likely to bathe his/her parent, simply because there is no one else around to do it (Warren, 2007).

A child caring for a parent who is ill is often an expectation of our society and is viewed as a positive aspect of children's development (Aldridge & Becker, 1999). However, the nature and extent of caregiving may be inappropriate for their age and developmental level (Aldridge & Becker, 1999; Ireland &

Pakenham, 2010; Warren, 2007). There is concern that when children care excessively or become caregivers in parental disability households, they are assuming adult nurturing roles during times when they themselves should be nurtured (De Judicibus & McCabe, 2004). Moreover, children who take on developmentally inappropriate roles within their households may become overwhelmed if the demands exceed their perceived resources to cope. Aldridge & Becker (1999) reported that the behavioural and social patterns required of child carers may place them be at a higher risk for anxiety, depression, and fear as compared to their peers.

In addition to caregiver responsibilities, a parental disability may also decrease opportunities for families to play together (Warren, 2007) and the child's involvement in community sports and recreation may be compromised due to economic circumstances, transportation barriers, or lack of leisure time (Warren, 2007). To the best of my knowledge, little research has examined the impact of parental MS on the play patterns and experiences of children who assume a caregiving role.

2. REVIEW OF LITERATURE

2.1 What is Multiple Sclerosis?

Our current understanding of multiple sclerosis (MS) is that it is an autoimmune disease that attacks the myelin sheath of nerves in the central nervous system (CNS) leaving plaques or scars. These scars result in the alteration of nerve conduction by slowing, redirecting, or stopping nerve impulses (Multiple Sclerosis Society of Canada, 2006). The exact etiology of MS is still unknown, although it is thought that a combination of genetic, infectious, environmental, and autoimmune factors likely contribute to the onset of the disease (White & Dressendorfer, 2004). MS is extremely variable, even hour to hour, and manifests itself depending on the areas of the CNS in which scars form (Motl, McAuley, & Snook, 2005). Some common symptoms of MS include loss of balance, gait alterations, impaired speech, extreme fatigue, double vision, and paralysis (Multiple Sclerosis Society of Canada, 2006; White & Dressendorfer, 2004).

There are four types of MS (a) relapsing-remitting, (b) primary progressive, (c) secondary progressive, and (d) chronic progressive (Multiple Sclerosis Society of Canada, 2006). Relapsing-remitting is characterized by periods of exacerbation where symptoms worsen, followed by a period of remission, where either partial or full recovery can occur. Primary progressive MS is characterized by a steady increase in symptoms and disability. With secondary progressive MS, about half of people diagnosed with relapsing-remitting MS will be diagnosed with secondary progressive MS approximately

ten years into their diagnosis. The difference from their initial diagnosis is that they no longer experience remission. Finally, chronic progressive MS is extremely rare and is characterized by a steady increase in symptoms along with exacerbations, and only slight remissions (Multiple Sclerosis Society of Canada, 2006).

Canada has one of the highest rates of MS in the world and it is the most common neurological disease affecting adult populations (Multiple Sclerosis Society of Canada, 2006). MS is a young adult's disease, with most diagnoses occurring between the ages of 15 and 40; the latter of which are considered to be prime-parenting years. In addition, women are more than three times as likely to develop MS compared to men (Multiple Sclerosis Society of Canada, 2006). No matter the gender or age of a person with MS, the impact is felt by family, friends and the community alike (Multiple Sclerosis Society of Canada, 2006). Activities once assumed by a parent may befall children as once routine activities can become challenging with the loss of function associated with the symptoms of MS.

2.2 Definition of a Young Caregiver

There is no consensus on the definition of a 'young caregiver.' The topic is complex and controversial as it involves disentangling typical roles of children within families from those which are excessive (Social Services Inspectorate, 1995; Thomas et al., 2003). The term 'young caregiver' is used to refer to a wide range of children and young people undertaking diverse activities in differing

circumstances (Read, 2002). While there is no universal definition, there is agreement that children ‘become’ caregivers when they are involved in exaggerated levels or forms of caring which have a restrictive or negative impact on their childhood (Aldridge & Becker, 1999). Exaggerated forms of caring may include intimate or personal caregiving for a parent such as bathing or toileting, dressing, transferring, administering medications, arranging doctor’s appointments. It could also involve psycho-emotional care such as providing emotional support, managing changes in personality, memory difficulties, or energy levels (Pakenham, 2007; Warren, 2007). Lackey & Gates (2001) found that personal care tasks such as bathing, toileting, dressing, and feeding were most difficult for the caregiver, while household tasks such as cleaning, cooking, babysitting siblings, and shopping were the most time consuming.

Exaggerated levels of caregiving may impact children’s performance at school because of absences, less time for homework, and lost sleep due to night time caregiving responsibilities. Additionally, exaggerated levels of caregiving may impact their play, recreation, and leisure activities, such as involvement in after-school sports, time with friends, or other extra-curricular activities (Lackey & Gates, 2001).

In 2004, Dearden and Becker published their third national survey of the characteristics of young caregivers across the UK. They collected data from a total 6,178 young carers – the largest survey of its kind. They found that 56% of the people surveyed were in lone-parent families and 70% of those lone-parents were mothers. Furthermore, they found that overall females were more involved

in all types of caring tasks, especially as the caregivers got older.

One explanation as to why more females are involved in caregiving comes from Suitor and Pillemer (2006). They described a consistent pattern of mothers' preferences of daughters over sons for sources of emotional and caregiver support, which may be attributed to shared values and gender-specific similarities.

In the early 1990s, young caregivers began attracting the attention of researchers (Aldridge & Becker, 1999). Estimates in 1996 were that 50 000 young carers existed in the United Kingdom (UK) (Aldridge & Becker, 1999). In 2005, a Young Carers report was released by the National Alliance for Caregiving (United States of America (USA)) and their estimate was that 1.3-1.4 million children in the USA live in a parental disability household and as many as 51,000 young caregivers exist in these households (National Alliance for Caregiving, 2005). In Australia, there are an estimated 347,666 young caregivers aged under 25 years (Australian Bureau of Statistics, 2003). Although Canadian statistics could not be located, the UK, USA, and Australian numbers could arguably be extrapolated to Canada. Baago (2004) noted that while British young caregivers have gained substantial public recognition and support throughout the UK at the socio-political level, their Canadian counterparts remain a hidden population.

It is difficult to estimate exactly how many young caregivers exist because they are unidentified in systems that might traditionally identify social problems, such as health, welfare, and educational agencies (Banks et al., 2001; Pakenham, Chiu, Bursnall, & Cannon, 2007; Thomas et al., 2003). As well, some children may be embarrassed or insecure about their home situation and may want to keep

it hidden. For example, children may not want to portray their parents as inadequate thereby threatening intervention by an outside agency. The idea of family separation may also be a concern (Thomas et al., 2003; Warren, 2007).

2.2.1 Why do Young Carers Exist?

Not all children who have a parent with disability will become young caregivers. Caregiving can be represented as a continuum from little or no caregiving to exaggerated levels of caregiving (Frank, 2002). There are numerous contributors to the phenomenon of child caregivers, such as the absence of one parent or the lack of a family support network. When a family has little or no extended or immediate family, children are more likely to take on the caregiver role for their parent (Aldridge, 1999). This may be particularly so for lone-parent households. Even if a family has a social network, they could be unsupportive or the lines of communication may not be adequate (Warren, 2007).

A second contributor to the existence of child caregivers is limited resources available for social welfare programs (e.g., home care). If there is no support in the form of a home care worker to visit the family and perform the more intimate duties such as bathing, a child caregiver may emerge (Aldridge, 1999; Warren, 2007).

A third contributor to the phenomenon of child caregivers is the family's socio-economic status (SES) (Warren, 2007). Although some people with MS may receive limited long-term disability support, it may not suffice in order to afford an attendant or other in-home supports. De Judicibus and McCabe (2004)

found that the lower the average family income, the more the impact of parental MS was felt by the family.

2.3 Mature Beyond her Years

Children who have a parent with MS are more likely than those from the wider community to mature emotionally sooner their peers (De Judicibus & McCabe, 2004). Arnaud (1959) asserted that young caregivers have a sense of “false maturity” (p. 18), meaning that while their responsibilities at home make them more mature, it occurs exponentially and at an early age, while their psychological and physical development remain typical. This discrepancy may lead to social isolation and behavioural and emotional maladjustment (Aldridge & Becker, 1999; Packenham & Bursnall, 2006). O’Neill (1985) defined this occurrence as “precocious competence” (p. 260). Further, one-third of children who care for a parent with MS have reported they perceived no choice in becoming their parents’ caregiver, which can intensify overall family stress (Packenham & Bursnall, 2006).

De Judicibus and McCabe (2004) studied parents’ perceptions of how their MS affected their children’s psychological health using the Strengths and Difficulties Questionnaire (Goodman, 1997, 1999). Twenty four boys and 24 girls (aged 4 to 16 years), and 5 male and 26 female parents with MS (aged 29-53 years, $M = 40.68$ years) completed a questionnaire package. The authors found that 12 children (25%) were rated by their parents as having clinically impaired functioning (e.g., hyperactivity, emotional symptoms, conduct problems). This

was in contrast to 7.5% which has been reported for community children (De Judicibus & McCabe, 2004, Goodman, 1999).

De Judicibus and McCabe (2004) also suggested the emotional maturity of caregivers may distance them from their peers:

Children, particularly daughters, of parents with MS are likely to be more attuned to the needs of adults, and to take more responsibility for helping others. They may, therefore, experience their peers as less mature, and relate better to adults than to other children (p. 564).

Power (1977) was interested in the experiences of adolescent caregivers who had a parent with a chronic disease. He interviewed 14 girls and 11 boys between the ages of 13 and 17 ($M=15$), all whom had a parent with Huntington's Disease, which, like MS, is a neurological condition. He visited the families at least four times for 90 minute periods prior to interviewing the participants and collected data over a period of eight months. While visiting the families, the author also completed participant observations, and administered selected testing instruments to discover the reactions and coping methods of the adolescents. The author concluded that adolescents' caregiving interfered with their peer relations. The caregivers found it difficult to relate to peers as they had taken on a role at home that was beyond the developmental level typical of their age.

Similarly, Lackey and Gates (2001) conducted a mixed method descriptive, retrospective study about the experiences of child caregivers. They conducted semi-structured interviews with 51 adults (age range 19-68 years when the study was conducted, 3-19 years old when they were in their caregiver roles) who were

caregivers for their family members diagnosed with cancer, stroke, cardiovascular disease, multiple sclerosis, amyotrophic lateral sclerosis, respiratory disease, diabetes, or arthritis. Demographic data were analyzed using descriptive statistics. The semi-structured interviews were analyzed using content analysis. The participants recalled their experiences as child caregivers and discussed how their caregiving changed the dynamics in their families' lives. One participant reported having "a brother who called me mother for about a year because he didn't know otherwise...I was about 14 at the time" (p. 324). Further, these caregivers reported often having older friends; one participant mentioned how her "grandpa's friends were [her] friends" (p. 324) because she was so mature, she could relate well to them. Others reported having friends that "understood" and were "supportive" (p. 324) of their caregiving role, while others were reluctant to tell friends of their caregiving responsibilities. Lackey and Gates concluded that it would be beneficial for young caregivers to be informed about their parents' illness and the nature and time commitment of caregiving tasks. They also stated that young caregivers need adequate support systems and their time as a "child" needs to be protected (p. 320).

Lackey and Gates' (2001) findings suggest that young caregivers have one foot in childhood and one foot in adulthood. At home their responsibilities resemble those of an adult, and outside the home they navigate social contexts as children. Caught in between these two worlds, children may find themselves overly mature for their peers, and yet too young to be doing all that they do at home. If young caregivers' periods of childhood are arguably shortened, it begs

the question as to how their experiences of growing up with a mother with MS might influence their experiences of play. Pellegrini, Dupuis, and Smith (2007) reported that both human and non-human animals play during their period of immaturity (childhood). If children assume caregiver roles during this period of immaturity, how might this impact their experiences of play?

2.4 Operational Definition of Play

There are many types of play and researchers agree that, given the complexity of the phenomenon, no one definition is necessary or sufficient (Martin & Caro, 1985; Pellegrini & Smith, 1998b; Rubin, Fein, & Vandenburg, 1983). Some researchers (Pellegrini & Smith, 1998a) have identified three main types of play, whereas others have identified up to 17 types of play (Hughes, 1999). For example, one type of play is fantasy play, which often involves acting out distinct roles (e.g., mommy, doctor) with the use of props. This type of play begins during the second year of life and peaks during late preschool years (Pellegrini & Smith, 1998b). Interestingly, Haight and Miller (1993) observed play in the homes of young children and found the mother plays an important supportive role in early fantasy play interactions. As well, children who are securely attached to their mothers engage in more sophisticated fantasy play, initiate more play interactions, and interact with their mother more positively compared to children who are insecurely attached (Roggman, Langlois, & Hubbs-Tait, 1987).

Another type of play is locomotor or physical activity play. This type of

play is physically vigorous and may include activities such as running, climbing, or jumping. It has been observed in preschoolers, but peaks in late childhood to account for 7-10% of free-time behaviour (Pellegrini, 1995).

Although there is no consensus on a definition of play, some play theorists agree on certain characteristics that are associated with play. They assert that play does not seem to serve any immediate purpose, but that the benefits of play (e.g., ability to appropriately navigate social contexts) are deferred until later in the child's life (Pellegrini & Smith, 1998b). This 'means over ends' component assumes that children are less concerned with the outcome of their decision to engage in play than with the behavioural processes that take place; thus play is intrinsically motivating (Pellegrini et al., 2007; Pellegrini & Smith, 1998b). A similar view of play is also supported by Hughes (1999) who purports that play is freely chosen and intrinsically motivating. Not all play researchers agree with this view and argue that "empirical studies of animal and human children's play have not provided strong or unequivocal evidence to support this claim" (Pellegrini & Smith, 1998b, p. 53). For example, children's play can be associated with a sense of mastery and self-efficacy, which may lead children to try new and novel activities. With self-efficacy to try the activities and repeatedly engage in them, children may learn new and specific skills (Bjorklund & Green, 1992; Pellegrini & Smith, 1998b).

In addition to the debate about deferred or immediate purpose, play has been classified according to circumstances that precede or succeed the activity (Rubin et al., 1983). One antecedent to play is context; the child has to be in a safe,

familiar context with a minimally intrusive adult, and he/she has to be free from hunger, stress, and fatigue (Rubin et al., 1983). Similarly, Martin and Bateson (1993) categorized behaviour in terms of spatial relations; behaviours, combined with the space they occur in, belong to a category if they take place concurrently. For example, behaviour that occurs at a playground is considered play.

Likewise, play has been considered in terms of its consequences or subsequent actions that occur (Pellegrini & Smith, 1998b). For instance, behaviour can be categorized as play fighting or rough and tumble play if children stay together following the 'fight'; whereas if they separate after the conclusion of the bout, it is considered aggression (Pellegrini & Smith). However, antecedents and consequences of actions can be considered as inducers and outcomes of play, respectively, rather than as components of the behaviour itself (Pellegrini & Smith).

Given the wide and divergent understandings of play, Tekin and Tekin (2007) suggest *that play is individually defined, depending on one's own play experiences and personal perspectives*. As young caregivers' experiences of play are not well understood, this inclusive definition of play is well suited to this exploratory study.

2.5 Importance of Play

It is well understood that play is not trivial; rather it is crucial for the health and well-being of children (Pellegrini & Smith, 1998a). Low levels of physically active play are associated with poor body composition and cardiovascular disease

(Rees et al., 2006). Relatedly, certain types of play (e.g., physical activity play) have been shown to be associated with fat reduction and improved thermoregulation (Pellegrini & Smith, 1998a). Physical activity play is also beneficial in that it provides opportunities for motor training, specifically muscular strength, cardiovascular training, and metabolic capacity (Pellegrini & Smith, 1998a). Aside from the physical benefits derived from play, engagement in play also contributes to children's psychological well-being (Parfitt & Eston, 2005), cognitive performance (e.g., heightened arousal, break-up of cognitive activities), friendships, social organization, and social skills (Pellegrini & Smith, 1998a).

According to Packer Isenberg and Quisenberry (2002), play has a crucial role in the optimal growth, learning, and development of children from infancy through adolescence. Play is culturally influenced and through participation, children not only learn about their culture, but preserve it as well (Hughes, 1999). Further, seminal play theorists such as Piaget (1964) and Vygotsky (1978) posit that play enables children to learn the skills necessary for optimal functioning in adulthood, such as cooperation, team work, and social functioning (encoding and decoding social signals).

When children play, they experiment with new and different activities, which allow them to explore their boundaries and learn their limits. This process of self-discovery contributes to feelings of mastery, self-awareness, and cognitive development, all of which have positive psychological implications (Pellegrini & Smith, 1998b). Additionally, Pellegrini et al. (2007) propose that when children

use play to sample their environment, they learn to develop adaptive behaviours in order to thrive in that environment. The unique nature of play is that it is quintessentially a child's activity, as it is initiated and controlled by children. This sense of autonomy can contribute to social competence, which has been linked to the development of resiliency in children and youth at risk (International Play Association [Canada], 2006).

2.6 Potential Barriers to Play Involvement

2.6.1 Parental Role Modeling

Researchers suggest that parents who are more physically active tend to have more physically active children due to overt encouragement and opportunities provided by the parents (Anderssen & Wold, 1992; Freedson & Evenson, 1991; Welk, Wood, & Morss, 2003). Gustafson and Rhodes (2006), in their review of parental correlates in children's physical activity, found role modeling to be a potential mechanism to influence children's engagement in physical activity. Others have found there is inconclusive evidence to support a positive association between parental role modelling and children's activity levels (Biddle & Goudas, 1996; Dempsey, Kimiecik, & Horn, 1993; Garcia, Broda, Frenn, Coviak, Pender, & Ronis, 1995). Further complicating parent role modelling are the various personal and/or environmental factors, along with the person's level of functioning, that impede participation in physical activity for persons with disabilities (Rimmer, 2006).

2.6.2 Transportation, Time, Money

Other factors that influence children's play are time spent outdoors and parents' ability to transport their children to facilities or activities (Welk et al.). Warren (2007) discussed how young caregivers are less likely to participate in sporting or recreational activities away from home due to financial and transportation barriers. Warren used cluster random sampling and conducted face-to-face structured interviews with 366 'non-caregiver' participants from youth clubs, educational establishments, the town's main shopping centre, and local residential areas (41% male, 59% female, $M=12.5$ years old). In addition, Warren selected 12 children and young adults from the same town because they were known to be young caregivers (4 males, 8 females, $M=13.8$ years old). The age range of participants was 9-18 years old. Interestingly, the demographics of these two groups were very different. The majority of the non-caregiver children lived in households where there were at least two adults, and where at least one adult was employed either full-time or part-time. Three-quarters of the young caregivers lived in lone-parent families exclusively with their mothers and two-thirds lived in households where no adult was employed. This information may be indicative of the ways in which the family context contributes to a child becoming a young caregiver.

Warren (2007) also found that when young caregivers participated in recreation and leisure activities away from the home, the activities were more likely to be based at school than in other community groups. They were less likely to undertake mainstream hobbies and interests, participate in sporting

activities, or join community groups, such as a youth club, music group, the Brownies, or Guides. The author concluded that the nature, frequency and time spent by young caregivers each week on domestic and caregiving tasks differs from that of other children and young people in the general population. Warren's study confirmed that young caregivers value a range of curricular and extracurricular school-based activities provided by education, youth and community services during lesson times, lunchtimes and after school. She stated that these professionals, therefore, have an important role to play in providing affordable, structured and unstructured community-based recreation and leisure activities that enable young caregivers to spend time away from their caregiving roles.

A limitation of Warren's (2007) study was the difficulty in recruiting young caregivers to participate because, as previously mentioned, they are currently unidentified in society, but also because some participants reported they feared intervention would lead to family separation. As well, her interviews with the participants only lasted six minutes, which may not be enough time to gather the required information about caregiving tasks to make the conclusions she did.

Given the breadth of research on children as caregivers, there is an "increasing acknowledgment of the need to assist and support family caregivers" (Cheung & Hocking, 2004, p. 153). Further, Antoun and Frank (2003) noted, "evidence of the extended family in providing care and support for individuals with disabling MS needs much more research, as does the potential use of children as young carers" (p. 804).

3. PURPOSE OF STUDY

Numerous researchers have examined the experiences of young caregivers (e.g., Aldridge & Becker, 1999; Antoun & Frank, 2003; Arnaud, 1959; Banks et al., 2001; De Judicibus & McCabe, 2004; Frank, 2002; Lackey & Gates, 2001; Olsen, 1996; Pakenham & Bursnall, 2006; Power, 1977; Thomas et al., 2003; Warren, 2007), but few have specifically examined the intersection of their experiences as caregivers of mothers with MS and play. Given the importance of play, the purpose of this study was to describe how daughters who are caregivers to their mothers with multiple sclerosis experienced play.

4. CONCEPTUAL FRAMEWORK

MS affects not only the individual who has the disease. It also impacts members of the family, as in the case of daughters who are caregivers for their moms (Cox & Paley, 2003). Researchers have called for a holistic and family-related approach to the impact of caregiving by children (Aldridge & Becker, 1999; Lackey & Gates, 2001). Moreover, “for those interested in the family, a systems approach is an essential conceptual tool” (Beavin Bavelas & Segal, 1982, p. 107). Family systems theory (FST) provides such a framework for understanding what a family is and how it functions (Turnbull & Turnbull, 1997) and was utilized as the conceptual framework to facilitate the interpretation of this study’s findings.

4.1 What is Family Systems Theory?

Family system theory emerged as a framework for clinical practice in family therapy in the 1950s (Beavin Bavelas & Segal, 2003). It expanded the focus of clinical practice and research from the individual to include patterns within whole family system in terms of interdependent relationship struggles rather than focusing on a fault of one person (Yerby, 1995). A fundamental component of FST is the recognition that what affects one member of the family, in turn, affects the whole family.

Satir (1972) used the metaphor of a mobile to explain the presence of subsystems within families and their interaction and interdependence:

In a mobile all the pieces, no matter what size or shape, can be grouped together and balanced by shortening or lengthening the strings attached or

rearranging the distance between the pieces. So it is with a family. None of the family members is identical to any other; they are all different and at different levels of growth. As in a mobile, you can't arrange one without thinking of the other. (Satir, 1972, pp. 119-120)

It may be useful to think of Satir's metaphor in terms of an individual living within an ecological system, namely her or his family (Beavin Bavelas & Segal, 1982). A family is a system as it is built around the relationships that are established, maintained, and communicated amongst its members. As such it is necessary to focus on the whole system (family) and see the parts only within the context of the whole (Beavin Bavelas & Segal).

Family systems theory is based on three key assumptions (a) the family is an open system which is an arrangement of input and output systems, (b) the family exists as a whole that is influenced by subsystems operating within it, and (c) boundaries define family subsystems and their roles (Cox & Paley, 2003; Turnbull & Turnbull, 1997). The first assumption of FST is that a family is an open system, and that specific characteristics of its members and environmental context provide input into the system. Moreover, family systems are adaptive and self-organizing and can adapt to change or challenge (Cox & Paley, 2003).

The interaction of the characteristics within the system (inputs) produces outputs that can be positive or negative in an attempt to stabilize the overall family system. In other words, changes that occur within families become part of a feedback loop that works to re-stabilize the family in some way (Kozlowska &

Hanney, 2002; Yerby, 1995). For example, the entire system (family) may react to a disruption in the system such as a child desiring to leave home through individual actions (Beavin Bavelas & Segal, 1982). Negative feedback is aimed at discouraging the child from leaving home whereas positive feedback is aimed at encouraging the new subsystem to develop and bring the family to a new level of stability. According to Beavin Bavelas & Segal (1982), the essential process is as follows:

A change begins and is detected by the system, which counteracts the change and the system restores homeostasis. In the end, nothing changes, because negative feedback is operating [child discouraged from leaving home]....A positive feedback process, on the other hand, will increase change over time....and the system is now reconstituted [child is encouraged to leave home and begin own life]....There is nothing inherently good or bad about either feedback system in a family; this depends on what the family wants and what works for its members at various stages in family life. (pp. 104-105)

In the case of a family who has a mother with MS, the behavioural characteristics of MS act as input characteristics. The family members then interact with that input, and their behaviours and reactions are considered the outputs. The particular output that was explored in this study was the daughters' of mothers with MS experiences of play.

The second fundamental assumption of FST is that the system must be

considered a whole and cannot be examined or understood by examining only its component parts (Turnbull & Turnbull, 1997). Within FST, families are characterized by circular actions of individuals who create a history and set of memories from which experiences are continually reconstructed. For example, a child's behaviour leads to the parent's behaviour who in turn leads to the child's, in a circular fashion (Beavin Bavelas, & Segal, 1982). As with theories that have been dominant for several decades, FST has undergone change. Rather than viewing family processes as circular that develop predictable patterns and resist change, they are now perceived as evolving with change being a constant in families (Yerby, 1995).

The components of the family as a whole that should also be taken into consideration are (a) its size and form; (b) cultural background, (c) socioeconomic status, and (d) geographic locations. Each component shapes the family's response to an input such as MS (Turnbull & Turnbull, 1997).

The third assumption inherent to FST is that families have a hierarchical structure (i.e., a family is composed of subsystems that are systems in and of themselves) (Cox & Paley, 2003). Subsystems within families (e.g., parents, siblings) are separated by boundaries. These boundaries are created and defined by the interaction of family members with each other and by the family unit interacting with outside influences (Turnbull & Turnbull, 1997). The family may have subsystems such as a child living away from home, spouses or ex-spouses, and extended family that have cross-generational characteristics (Beavin Bavelas & Segal, 1982).

If a child is a caregiver for her mother, “such children may be brought into the parental subsystem” and the boundaries between parent and child subsystems may be blurred (Turnbull & Turnbull, 1997, p. 48). Boundaries are different for different families and they can change as the family changes. For example, a 12-year old child’s boundaries with her parents are likely much different when she is 22 years old. In addition, two sisters’ boundaries with each other might be very different from those with their brother. Finally, a particular family unit may have more narrow boundaries with outside influences (e.g., a church, health care worker) than the next family unit. For example, as many as 80% of people with MS experience depression at some point in their lives (MS Society of Canada, 2006), suggesting that the support of psychologists or psychiatrists may be required. A family’s boundaries with this outside influence may be different than a family unit that is not living with MS.

FST (Turnbull & Turnbull, 1997) aided in discovering the meaning behind the stories collected through this research. This theory fits well with this study as an attempt was made to understand the daughters’ play experiences (an output) and how they might have been influenced by their mother’s characteristic of having MS (an input). Beyond that, FST was a good heuristic tool to ensure we were learning about the *whole* family. The dynamics of the family were uncovered through the daughter’s perspective for this project, not the people directly affected with MS. FST also reminded us about the importance of the researcher being respectful of a family’s boundaries when interacting with outside influences, and that boundaries within a family system can help reveal

information about that family. These boundaries also help provide context when trying to understand a family's perspectives.

5. METHODOLOGY

5.1 Research Tradition

My research question was investigated using a qualitative approach. Qualitative researchers study people in their natural settings and attempt to interpret phenomena in terms of the meaning and significance participants bring to them. Qualitative researchers are interested in how people perceive their experiences, their worlds, and what significance they attribute to their lives and experience (van Manen, 1997). Their findings and interpretations make the world visible (Denzin & Lincoln, 2005).

The approach to my study was informed by phenomenology. A phenomenological study describes the meaning of people's lived experiences (Creswell, 2007). Researchers attempt to describe shared occurrences and "grasp the very nature of the thing" (van Manen, 1997, p. 163) across its many variations (Miles & Huberman, 1994).

Phenomenology is a qualitative approach well suited to families with parental disability. Toombs (1995), who has MS, suggested that phenomenology can provide important insights into the profound disruptions that are an inevitable manifestation of MS. Moreover, I was interested in learning more about the everyday play experiences of daughters who have mothers with MS from the *daughters'* perspectives. It is important to know what they experience and how they make sense of their world (Patton, 2002). According to van Manen (1997), phenomenologists are less interested in the factual status of particular instances and are more interested in "anything that presents itself to consciousness...as

consciousness is the only access human beings have to the world” (p. 9). Finally, as Yerby (1995, p. 339) stated: “...we have much to gain by adopting an interpretive, narrative framework for studying communication in family systems.”

5.2 Participants

Qualitative research can focus on small purposefully selected samples that are information-rich (i.e., are involved in the phenomenon being studied), which allow for an in-depth understanding of the question under study (Denzin & Lincoln, 1994; Patton, 2002). Creswell (2007) recommends 3-10 participants for a phenomenologically informed study.

The age range of 18-26 was carefully selected in that the participants were all adults, yet close enough to the experience of childhood that recall bias should have been less of a concern. It was important that the participants were phasing out or already out of their caregiver role because, as van Manen (1997) states, “a person cannot reflect on lived experience while living through the experience” and that “reflection on lived experience is always recollective; it is reflection on experience that is already passed or lived through” (p. 10).

Before any data collection began, ethical approval was obtained from the Faculty of Physical Education and Recreation and Agricultural, Life and Environmental Sciences Research Ethics Board at the University of Alberta (see Appendix A: Ethics Approval Certificate). Each of the participants was fully informed of the purpose of the study, what involvement would entail, and was given an information letter (see Appendix B: Participant Information Letter). All

of the participants gave written informed consent prior to the initiation of data collection.

5.2.1 Sampling Strategy

Purposeful sampling can be performed using different strategies, each serving a particular purpose (Patton, 2002). For this study, criterion sampling was utilized. In this sampling strategy, participants are selected because they meet a pre-determined set of criterion to ensure they are representative of the phenomenon of interest (Creswell, 2007). Following is the sampling criteria that were used to choose the participants that had lived experiences of the phenomenon of interest:

- (a) Had a mother with MS. In Dearden and Becker's (2004) report on young carers in the UK, they found that the majority of people with care needs were mothers.
- (b) Was female. Given that mothers tend to prefer daughters' support over their sons (Suitor & Pillemer, 2006), it is plausible that daughters of a same-sex parent with a disability may have qualitatively different play experiences than those of their male siblings, and may be more likely to take on a caregiving role for their mother.
- (c) Age range=18-26 years. Pakenham and Bursnall (2006) cite this as an appropriate age range for young caregiver participants, as it reflects the increased age of children living at home with their parents.
- (d) Provided caregiver role, as identified by equal to or higher than 'MS

Young Carer' mean score on Young Carers of Parents Inventory (YCOPI) (Pakenham, Bursanll, Chiu, Cannon, & Okochi, 2006) (see Appendix C). YCOPI consists of two age-appropriate questionnaires that were developed for participants aged 10–13 years and 14–25 years. The two sets of questionnaires are identical except for several words that were changed to make them more age appropriate. Participants rate the extent to which they agree with each item using a 5-point scale ranging from 0 (*strongly disagree*) to 4 (*strongly agree*). Pakenham et al. (2006) have reported that this measure has reliable factors (range .71–.91) which describe the diverse impacts of young caregiving (caregiving responsibilities, perceived maturity, worry about parents, activity restrictions, isolation (Part A), caregiving compulsion, caregiving discomfort, and caregiving confidence (Part B)). The five factors on Part A accounted for 61.10% of the variance, and the three factors on Part B accounted for 62.44% of the variance. All of the participants were considered to be caregivers according to the YCOPI as they exceeded the MS Young Carer mean scores on Part A (Norm Mean (MS Young Carers) = 9.5). Their scores were 9.92 (Pam), 22.53 (Holly), 10.77 (Elizabeth) and 14.38 (Haley). All but one participant exceeded the MS Young Carer mean scores on Part B (Norm Mean (MS Young Carer) = 5.01). Their scores were 4.6 (Pam), 8.27 (Holly), 7.47 (Elizabeth), and 5.93 (Haley). As Part B is only filled out by those who have a parent with an illness or disability, it can be concluded that Pam

can still be considered a caregiver (given Part A score), but perhaps her role is perceived as not as intense as other children of parents with MS.

- (e) The caregiver role was provided in the context of a lone-parent family, as Dearden and Becker (2004) found that mothers accounted for 70% of people needing care in lone-parent families. As well, it is plausible that lone-parent families might have a different experience than two-parent families, especially in the context of a daughter providing care to her mother. Two of the participants were from lone-parent families during the period they were caregivers for their mothers. The other two participants experienced being in a lone-parent family for a time before their mothers remarried.

No restriction on the type of MS was imposed. This enabled me to explore and describe the participants' stories irrespective of the type of MS. This criterion enhances the transferability of the study, as the findings can be more easily applied to families with MS of varying life circumstances. Creswell (2007) notes that when participant variability on a criterion is maximized at the beginning of the study, there is increased likelihood that the findings will capture differences and different perspectives. This strategy was particularly salient for studying MS as it is an extremely variable disease, not only in symptom manifestation across person to person, but also for each person. Wellness can change from one hour to the next for a person living with MS (National Multiple Sclerosis Society, 2007).

Participants were not eligible for the study if their family received homecare or in-home help more than two hours per weekday. The upper limit of two hours

per day was arrived at through an informal conversation with one of the participants, Holly. She and her mother had home care come for two hours per day and yet Holly still defined herself as her mother's caregiver. As the participants were from a household where the only adult had MS, it was plausible that their families might receive some paid home care assistance.

5.2.2 Recruitment Strategy

I held the joint MS ActiveNOW fellowship with the MS Society of Canada (Edmonton Chapter) (MS Society) and The Steadward Centre for Personal and Physical Achievement (TSC), Faculty of Physical Education and Recreation from January 2006 to June 2007. The purpose of the Fellowship was to increase wellness opportunities for people living with MS in Edmonton and the surrounding area. I had the opportunity to work both with MS Society clients and TSC members with MS. Over the 18 months I was in this position, I was fortunate enough to develop several meaningful relationships with both people living with MS and my colleagues at the MS Society and TSC. I contacted the Director of Client Services at the MS Society and the Program Director at TSC to inform them of the study and I received their support for participant recruitment. I attended several MS Society support group meetings and the TSC Stretch and Tone program where I discussed my study. Women who had daughters who might be eligible for the study were provided with an information brochure. I asked them to discuss the study with their daughter(s) and have them contact me if they were interested in participating. Two of the participants came from my

attendance at MS Society support group meetings. The third participant was a friend of a fellow graduate student. I was discussing my study with this graduate student and she said she knew someone who might be eligible. I asked her to contact the potential participant, which she did, and passed along the participant's information to me with permission. Finally, the fourth participant is a friend of mine. She was the inspiration for the study and she was eager to participate in the study.

5.2.3 Description of the Participants

The four participants for this study were female Canadian Caucasian caregivers of mothers with MS from lone-parent families between 19 and 26 years of age. One participant was living at home at the time of the study. Information of the components of the families represented in this study was collected using a demographic information form (see Appendix D). Understanding the family is necessary to appropriately understand the child's perspective, as a family consists of all its members and the combination of their interactions (Turnbull & Turnbull, 1997).

Pam was 23 years old at the time of the study. She lived on her own and was working full-time as a legal secretary, and had taken post secondary education. She had a half-brother who was 16 years-old and a step-sister who was 20 years old. She reported that she was physically active weekly and participated in Pilates, water aerobics, and walking.

We did not live in the same city, so I traveled to the neighbouring province

to conduct her one-on-one interview at her home. Pam's mom was diagnosed with relapsing-remitting MS when Pam was seven years old. At the time of diagnosis, Pam's mom was just about to get re-married and their house was undergoing renovations; a very chaotic time for their family. Further, they had a trip to Disneyland planned, which was cancelled when Pam's mom became ill. Pam was really sad her visit with Mickey Mouse was put on hold – a memory that stayed with her. Her mom was hospitalized for three months after her diagnosis. Pam's step-dad and his parents looked after her during this time. Pam reported that while her step-dad and his parents were supportive, she didn't really get along with her step-dad for the most part, and remembered how she never wanted to be at home while growing up. Pam's mom and her step-dad got divorced when Pam was 17 years old.

Pam indicated that her mom currently does not use any mobility devices however; she experiences symptoms of fatigue, numbness, and vision problems. She also requires regular naps and has been in remission for a long time. Her MS is fairly well controlled through medication that is taken via injections. Pam reported that her mom was physically active weekly, participating in Pilates and walking as much as she was able.

Holly was 26 years old at the time of our one-on-one interview, which took place in her townhouse that she shared with her husband. She had a lot on her mind at the time and for this she was apologetic. She was planning on buying a car later that night and was getting ready to go on her honeymoon in two weeks to a place that was experiencing political turmoil. Holly had a university degree and

worked full-time for the municipal government. She seemed to be a busy person as when she attended the group interview, she had come from a full day of meetings. Holly reported that she was physically active weekly, taking part in yoga, walking and rollerblading.

Holly's mom was diagnosed with relapsing-remitting MS when Holly was 11 years old. Growing up, Holly was the only support her mom had, apart from home care visits each morning. Her mom used a wheelchair for the first five years following her diagnosis. She currently uses a walker or cane to get around. Holly reported that her symptoms included fatigue; balance difficulties, periodic speech difficulties, left side paralysis, and optic neuritis in vision can become periodically blurry due to inflammation of the optic nerve. Holly indicated her mom was physically active monthly, walking and going to the gym in her building to complete stretches.

Holly has always had a good support network of friends and spent a considerable amount of time with her friend's family, but her mom's support network did not develop until Holly left home for four months in 2006. In Holly's absence, her mom had learned to rely on others for support and upon returning home, Holly felt comfortable enough to move out of her mom's house. Currently Holly still considers herself responsible should anything happen to her mom.

Elizabeth was my youngest participant, at 19 years of age. She was living with her mom, assuming the role of her mom's caregiver. The interviews were very emotional for Elizabeth, I believe because her stories were still very fresh.

Elizabeth's mom was diagnosed with relapsing-remitting MS only 18 months prior to Elizabeth's interview. Elizabeth indicated that her mom's symptoms include fatigue, headaches, and altered speech and balance. Elizabeth was very happy to meet women who grew up in similar situations to her, and keen to mentor other young caregivers.

Elizabeth was very athletic growing up, and was involved with many team sports in high school. She reported she was no longer involved in sports so she could support her mom. She was, however, still physically active weekly, with walking, physical activity classes at university, and going to the gym. Elizabeth lead a full life as she had a boyfriend at the time of the interview, worked part-time as a physiotherapy assistant, and was attending university full-time. She discussed how she was unable to share her experiences of caregiving for her mom with MS with her friends because they apparently didn't understand. She stated that her mom was not physically active.

Haley was 23 years old and quite reluctant to participate in this study. She, at first, didn't want to be interviewed face-to-face, I think because she is naturally a private person and I was a stranger to her. However, in the end she was glad to have the opportunity to talk about her experiences of supporting her mom with MS and thanked me for including her in the study. She didn't participate in the group interview as she said she wasn't comfortable in groups. Haley had a high school education, no longer lived at home, and worked full-time at a mountain resort.

The one-on-one interview took place in the living room of her staff

accommodations. To begin, the TV was on and a co-worker was doing something in the adjacent kitchen. Thankfully once the paper work portion of the interview was over, the co-worker had finished and I asked if we could turn the TV off, which may have been on to keep our conversation private while the co-worker was there.

Haley's mom was diagnosed approximately in 2000 (Haley had trouble remembering), which would mean she was around the age of 15. Her parents divorced when she was six. Her mom remarried her step-dad (whom I believe she refers to as dad) before she was diagnosed with MS. At one point Haley's mom and step-dad separated, at which time it was just Haley and her mom and two younger sisters, as her brother (aged 21) had gone to live with their biological dad. Haley's parents got back together, which allowed Haley the freedom to move away for work. Haley's stories included experiences of depression as a teenager which was complicated by her realisation that her mom needed her support to deal with MS and her mom's own depression.

Haley felt she wasn't as physically active growing up because she shut herself away as a way of coping with her mom's MS. Neither Haley nor her mom were physically active at the time of the study. Haley reported her mom had progressive MS, and experienced symptoms of over-sleeping, pain, and memory loss (mostly short-term). Haley indicated that a friend of her mom's who also had MS and has been a great support for both of them.

5.3 Data Collection

In naturalistic inquiry, qualitative data can consist of quotations obtained from interviews, observations documented through field notes, and artefacts such as excerpts from documents (Patton, 2002). As Creswell (2007) notes, artefact data may also be in the form of art, music, photographs, or personal family collections. Obtaining data from several sources brings various perspectives forward and enables the researcher to better understand the essence of the experiences being studied (Erlandson, Harris, Skipper, & Allen, 1993).

Creswell (2007) encourages the use of new and creative data collection methods. The data for this study was collected through demographic information, one-on-one and focus group interviews, field notes, and artefacts. When I conducted the one-on-one interviews with the participants, I asked if they would find benefit in participating in a focus group interview, and three out of four said this would be of interest to them.

The family context was discussed as part of the demographic information that was collected. It was important to know about the participants' co-residency status (who they live with) (Warren, 2007), socioeconomic status (De Judicibus & McCabe, 2004), cultural background, geographic location, and the nature of their support network (Turnbull & Turnbull, 1997; Warren 2007).

5.3.1 Interviews

According to Creswell (2007), data collection in phenomenologically informed studies often consists of in-depth interviews with participants who have

experienced the phenomenon under study. Moreover, researchers interview people to find out information that they cannot directly observe, such as feelings, thoughts, and intentions (Patton, 2002). As well, interviews allow the researcher to enter into the other person's perspective. To accomplish this we must acknowledge the assumption that their perspective is meaningful, knowable, and able to be articulated (Patton). There are three basic types of interviews (a) structured, (b) semi-structured, and (c) unstructured (Fontana & Frey, 1994). Structured interviews consist of the same carefully worded questions and take each participant through the same sequence, with a limited set of response categories (Fontana & Frey, Patton). A semi-structured interview has a series of topics to be covered with suggested questions (Kvale, 1996). Finally, an unstructured interview, also known as the informal conversational interview, is the most open-ended approach and offers maximum flexibility to pursue information in whatever direction is deemed appropriate, depending on what emerges during the exchange (Patton).

The purpose of the qualitative research interview is to obtain descriptions of the participants' world and interpret their meaning and significance associated with that world (Kvale, 1996). Researchers have found (e.g., Lackey & Gates, 1997) semi-structured phenomenological interviews allowed them to focus on the experience and feelings of adolescents, thus providing participant-centred description of parental disability and what it meant. The participants in this study took part in two audio-taped interviews; the first being a one-on-one semi-structured interview, the second being a focus group interview. The focus group

interview provided a forum for the participants to discuss selected artefacts that represented their experiences of play.

5.3.1.1 One-on-One Interviews

Each participant engaged in one face-to-face semi-structured interview between 60 and 90 minutes in duration. The semi-structured interview gave the freedom to pursue areas of interest and follow the responses of the participants. The one-on-one interviews also provided the opportunity to probe any relevant areas that emerged (Smith, 1995). I used an interview guide (see Appendix E) to ensure the same basic lines of inquiry were covered with each participant and provided topics which I was free to explore, probe, and ask questions that illuminated that particular subject area (Patton, 2002). I took advantage of the inherent flexibility in a semi-structured interview to change the sequence and forms of questions in order to follow up given answers and stories told by the participants (Kvale, 1996).

The interview guide also helped in making the best use of time as it assisted with keeping the discussion focused on the research question. It kept interactions on topic whilst allowing individual perspectives to emerge (Patton, 2002).

Prior to conducting the interviews, I received feedback from my supervisor, looked to the conceptual framework in formulating my questions, and asked two fellow graduate students also in adapted physical activity to provide input. One of the participants also reviewed the interview guide during its development. All of the feedback provided was incorporated into the final interview guide.

All of the above mentioned interviews were audio-taped and conducted in a location that was mutually agreed upon by the participants and myself (Creswell, 2007).

5.3.1.2 Focus Group Interview

Three of the participants agreed to participate in a focus group interview that lasted 90 minutes. The focus group was unstructured, as is appropriate for phenomenologically informed studies (Frey & Fontana, 1994). Focus group interviews elicit the exchange of beliefs and attitudes between people who experience similar situations, enable the researcher to gain a richer understanding of the issues being discussed, and can offer a more natural environment for storytelling than one-on-one interviewing (Madriz, 2000). As well, the interactions between participants can sensitize the researcher to issues which may not have been previously considered, which is especially relevant if the researcher is an outsider (Belgrave & Smith, 2002). In this study, I was an outsider as I did not experience play in the context of being the caregiver for my mother with MS.

Frey and Fontana (1994) contend that a group interview, or a focus group, is not meant to replace the one-on-one interview, but it is an option that can provide a means by which the participants can explore their experiences through dialogue with others, in this case daughters of mothers with MS. This dialogue is not available through one-on-one interviews.

The focus group interview was also used as a strategy to appropriately exit the field. As the daughters were introduced to other daughters who were also

living with a mother with MS; it served as an opportunity to illuminate the fact that they were not ‘the only ones’. Holly and Elizabeth were in the same room for the focus group interview and Pam participated over the phone. While it would have been better if we could have had Pam in the room to meet other daughters of mothers with MS in person, it was still good that she could be part of the conversation over the phone. As she could not see the faces of the other daughters, I sometimes had to explain facial expressions or hand gestures to Pam so she had a richer understanding of what was being conveyed.

Haley chose not to participate in this interview as she did not feel comfortable “talking about this in front of a lot of people”. There was a period of four months between the first one-on-one interview and the focus group interview.

5.3.2 Artefacts

Polkinghorne (1989) supports gathering information from representations of the experience outside the context of the interview context as it provides an opportunity for the participants to have the freedom to offer a representation of their experience that is not structured by the researcher. The participants were invited to bring artefacts to the second (focus group) interview that represented their experience(s) of play while growing up. The intent of the artefacts was to help the participants tell their stories (Patton, 2002). The stories surrounding their artefacts not only added to the data collected, but also served to ‘break the ice’ at the beginning of the interview, which was particularly beneficial in the focus

group. The daughters were invited to bring items such as a diary or journal, artwork, sports equipment, a poem, or a picture that represented their experiences of play growing up. The daughters' artefacts included a card made by Elizabeth's rugby team for her mom, Pam's mom's baseball glove, a 'cookie' that Pam baked with her step-dad, a deck of cards that Holly played with her mom, and a photograph from Holly's jazz class. Bogdan and Biklen (1998) assert these supplementary sources of information add to the trustworthiness of the findings.

5.3.3 Field Notes

Field notes contain the description of what has been observed and should contain everything the researcher believes to be noteworthy, including his/her own reactions, reflections, and interpretations (Patton, 2002).

Field notes were recorded following the interviews. Very brief notes were taken during the interview, so as not to detract from the conversation. More detailed notes were jotted down and expanded upon following the conclusion of each interview. These notes allowed for reflection on the conversation, thoughts for further probing with subsequent participants, and analyses about what was happening in the setting and its significance (Patton, 2002). I kept a reflexive journal, which noted thoughts, feelings, and emerging interpretations.

5.4 Data Analysis

5.4.1 Interviews

Qualitative data analysis is the process of taking all that has been read,

observed, and heard and making meaning of it all; the ‘lessons learned’ (Lincoln & Guba, 1985), or as Patton (2002) puts it, data analysis transforms data into findings. Miles and Huberman (1994) posit that data analysis occurs continuously throughout any qualitative project, sometimes without the researcher even knowing it. For instance, the researcher chooses which cases to examine, which research questions to ask, and which data collection approaches to use, which all involve reducing the data. Data reduction, or determining consistencies, meanings, and significance (Patton), is not something separate from analysis; rather it is *part* of analysis (Miles & Huberman, 1994).

In a phenomenologically informed study, data is typically analyzed thematically (van Manen, 1997). According to van Manen, thematic analysis is “a free act of ‘seeing’ meaning” (p. 79) or a systematic and organized process of developing meaning. In other words, researchers describe themes through some classification system, and present an interpretation in their own view or with the support of the literature (Creswell, 2007).

For this study, the data was analyzed thematically line-by-line. The general analysis process undertaken and suggested by Miles and Huberman (1994), Patton (2002), and Wolcott (1994) is as follows:

- The one-on-one and focus group interviews were transcribed verbatim.
- I read and re-read the transcripts.
- I then reduced the volume of data by discriminating significance from trivia. As Wolcott (1994) suggested, I highlighted phrases that were deemed significant. I had to make choices and single out that which

was worthy of note (Wolcott), always keeping in mind the *purpose* of the study as purpose guides analysis (Patton, 2002). To do this, I had to constantly ask myself: “is this relevant to the account” (Wolcott, 1994, p. 14) and look at data through the lens of this particular study, noting reflections or other comments in the margins (Miles & Huberman, 1994).

- Next I read through the highlighted material to recognize similar phrases and patterns. Patton (2002) defines patterns as core meanings. When patterns were identified, I then attached codes to phrases. Codes were tags for retrieving recognized patterns. As well, codes could be explicit or metaphorical. Patton states that assigning codes to recognized patterns is a more descriptive and less interpretive step of the analysis process. The codes were developed inductively, or as Strauss & Corbin (1998) put it, “open coding” (p. 223), where I was open to the data and allowed findings to emerge (Patton, 2002). Open coding avoids limiting the analysis to prefigured categories and gives the participants as much voice as possible (Creswell, 2007). Additionally, “in vivo” codes (Bernard & Ryan, 1998, p. 608), or participant-offered terms were used before analyst-offered codes (Patton).
- Once codes were attached, I took a step toward a more interpretive phase of the analysis and assigned labels to clusters of codes that were conceptually similar. While codes *identified* patterns, labels assigned

units of meaning to the information compiled (Miles & Huberman, 1994). I then made comparisons as to what codes belonged under what label based on two criteria: (1) internal homogeneity; and (2) external homogeneity. Internal homogeneity dealt with the extent to which the data under a certain label were similar in a meaningful way, and external homogeneity was the notion that one label was significantly and conceptually different from the next (Patton, 2002).

- Finally, I moved further in the interpretive phase of analysis and extracted meanings from labels by developing themes. A theme is a common thread that runs through the data, occurring at different points and in different forms, yet nonetheless present (Morse & Richards, 2002). It is the interpretation of data that extracts meaning about the phenomenon of interest (Patton, 2002).

5.4.2 Artefacts

Artefacts were used to stimulate discussion about the participants' experiences of play during the focus group interview (Patton, 2002). The discussions were captured on the audio tape and transcribed as part of the raw data and as such became part of the interview data analysis.

5.4.3 Field Notes

Prior to the analysis and during interpretation, I reviewed my field notes. This enabled me to return to the interview settings in my mind and assisted in my

capturing and recalling the tone and depth of the conversations. The field notes placed me back into the emotional context of my conversations with the participants (Patton, 2002). The field notes themselves were not coded, but helped me to re-contextualise during the analysis and interpretation stages.

6. TRUSTWORTHINESS OF QUALITATIVE RESEARCH

Trustworthiness refers to the quality of a study and its findings that make it valuable to those concerned (Schwandt, 1997). “Without rigor, research is worthless, becomes fiction, and loses its utility” (Morse, Barrett, Mayan, Olson, & Spiers, 2002, p. 2). There are several strategies that qualitative researchers utilize to ensure their work is trustworthy. This study used the trustworthiness strategies of credibility (Lincoln & Guba, 1985), as well as the emerging criteria of positionality, voice, critical subjectivity, reciprocity, sacredness, and sharing the perquisites of privilege (Lincoln, 1995).

The emerging criteria were developed because the “foundational” criteria of trustworthiness were rooted in assumptions that had been developed for an empiricist research philosophy and criteria parallels between empiricist and interpretive research are no longer required (Lincoln, 1995, p. 276). Moreover, Ely, Anzul, Friedman, and Garner (1991) believed that maintaining quantitative terms of validity, reliability, and generalizability was an attempt to ‘prove’ to traditional quantitative researchers that qualitative research can meet the same standards. They believed that the quantitative language was incongruent to the work qualitative researchers undertake. A summary of the trustworthiness criteria undertaken in this study are presented in Table 1.

Table 1

Overview of Trustworthiness Criteria

Trustworthiness criteria	Application to study
1. Credibility	Triangulation of data method and sources Peer de-briefing Purposive criterion based sampling Member checks with participants
2. Positionality	Honesty about researcher's position Detailed description of participants and their setting
3. Voice	Presentation of findings Interview guide development assistance Negative case analysis
4. Critical Subjectivity	Reflexive journal
5. Reciprocity	Openness about researcher's position Member checks with participants Focus group interview
6. Sacredness	Collaborative approach
7. Sharing Perquisites of Privilege	Provide copy of thesis to participants Acknowledgement of participants in manuscript(s) and its defence Linking of participants with each other

6.1 Credibility

In a phenomenologically informed study, researcher *re*constructions of a lived experience should be arrived in such a way that they are believable or convincing, hence *credible* reflections of the original constructors of the participants' realities (Lincoln & Guba, 1985). Lincoln and Guba (1985) outlined techniques to enhance credibility, including (a) data triangulation, (b) an external check on the research process (e.g., peer de-briefing), and (c) direct discussions of the findings and their interpretations with the participants or human data source (member checks).

To triangulate data, I used multiple methods of data collection to gather supporting evidence about the essence of the lived experiences of play as a caregiver (Creswell, 2007; Denzin, 1989). Information was gathered from one-on-one and focus group interviews, artefacts, and field note information. The stories behind the artefacts were used as a way to triangulate the interview data as they offered an alternate format for the participants to share their experiences. It is important to collect data in various ways as each method may reveal a different aspect about the experience, thus augmenting knowledge about the phenomenon under study. As well, multiple types of data allow for cross-data consistency checks to counter inaccuracies due to loaded interview questions or unrepresentative responses (Patton, 2002).

To further triangulate the data, multiple data sources were present in the study. Four participants who had deep experiences as caregivers shared their lived experiences (Creswell, 2007).

Having a “devil’s advocate” peer to debrief the inquiry process created an external check of the research process and treatment of the findings (Creswell, 2007; Lincoln & Guba, 1985). This competent, arms-length person asked tough questions about methods, potential biases, and listened to my concerns and feelings (Creswell, Lincoln & Guba). For this study, my devil’s advocate peer was my supervisor, Dr. Donna Goodwin.

Purposive criterion-based sampling was important in ensuring credibility. Purposive sampling enabled the researcher to examine information-rich cases, or individuals who have actually experienced the phenomenon, to gain a deeper understanding of the phenomenon of interest (Creswell, 2007; Patton, 2002). For example, to be eligible for the study, participants had to be caregivers for their mothers with MS.

6.1.1 Member Checking

According to Lincoln and Guba (1985), performing a member check—where the data, analysis, interpretations, and conclusions are confirmed with the original human sources—is the “most crucial technique for establishing credibility” (p. 314). If the researcher is willing to posit that his/her interpretations and conclusions of the lived experience are adequate, those who have lived the experience ought to have the chance to corroborate these positions (Lincoln & Guba). This process can be formal or informal and can involve the researcher summarizing an interview with a participant, or asking a participant to comment on an emerging preliminary theme (Creswell, 2007).

Member checking involved a three stage process. The interviews were transcribed verbatim and provided to the participants so they could verify that the transcripts accurately reflected what they said or would like to have said. All the participants confirmed that the transcripts were accurate representations of their interviews⁴.

Once the data was analyzed, the results section of the thesis was written. I then sent the first draft of the results section to all four participants via email to read and comment. I received written comments shortly after from one participant and re-sent the results section to the other three participants. I heard from the other three participants following the second email. All participants stated that the results accurately and honestly represented their experiences of play in the context of having a mother with MS.

The third stage occurred following feedback from my supervisor on the presentation of the results. I set-up face-to-face meetings with one of the daughters who lived in the same city as me to review a second draft of the results and further discuss her reactions and thoughts about the representation of her stories. Email “meetings” were held with the other daughters. The daughters reaffirmed that each theme was an integral part of their play experiences while they were caregivers for their mothers with MS.

6.2 Positionality

As part of the rapport building process with both the participants and readers of this work, the researcher’s position in the research process (e.g.,

⁴ As Haley did not participate in the focus group, she did not receive the focus group transcript.

experiences, background) was shared with the participants at the time of both the interviews and was included in the introduction of this manuscript. The notion of positionality accounts for the fact that texts are always socially, culturally, historically, racially, and sexually located and can only represent the perceptions of those who exhibit the same characteristics (Lincoln, 1995). In other words, because qualitative researchers *interpret* a phenomenon, they are directly involved with the findings of a study; their own experiences and background influence their perceptions and thus interpretations (Creswell, 2007).

Demographic information on each participant (e.g., age, physical activity interests, occupation, mothers' types of MS) was collected prior to the one-on-one interviews. By including such detailed information, it affords readers the opportunity to make decisions about the transferability of the findings to other people and settings (Lincoln, 1995).

6.3 Voice

Voice is an important criterion in judging quality of research as it provides those who do not have access to academic disciplines the opportunity to be heard (Lincoln, 1995). Voice can be viewed as resistance against silence, resistance to disengagement, and resistance to marginalization. Recognition of voice in the research process can portray a passionate researcher committed to openness of multiple voices and interpretations (Lincoln). The voices and words of the participants in this study were primarily heard through the stories that emerged during the one-on-one semi-structured interviews, the unstructured focus group

interview, and the analysis and presentation of findings. In the member checking process, the participants had the opportunity to confirm or deny a thematic interpretation as being reflective of their experiences.

6.4 Critical Subjectivity

Reflexivity is the ability to be very aware or conscious of one's personal and psychological states, as well as those of the participants, before, during, and after the research experience (Lincoln, 1995). In order to support reflexivity, a journal was kept. This reflexive journal documented feelings, thoughts, perspectives, context, and biases toward any aspect of the study. It helped to ensure the analysis and interpretations accurately reflected the participants' experiences, and was not merely a reproduction of my potential biases (Lincoln). Such reflexivity also enabled me to uncover patterns and similarities, as well as contradictions within the stories told by participants.

6.5 Reciprocity

Reciprocity is the acknowledgement that not only do participants affect the field of study, but so do the researchers as they are an integral part of the people-centred nature of qualitative research (Lincoln, 1995). There exists an intense sharing, trust, and mutuality between participant and investigator (Creswell, 2007). The daughters were informed about my context and how I came to this research question, therefore establishing openness and honesty in the dialoguing process. They were invited to review transcripts, analysis, and interpretations as

part of the member checking process, playing an integral role in developing what was conveyed about their experiences. It is my hope that this process contributed to a sense of trust and mutuality between the participants and me.

6.6 Sacredness

Qualitative researchers often have a profound concern for human dignity, justice, and respect, which may have led them to this form of inquiry in the first place (Lincoln, 1995). It is important that researchers respect the sacredness of egalitarian and collaborative relationships in the research-to-action continuum (Lincoln).

The daughters were viewed as collaborators in the research process; in other words, we were a team and explored their experiences together. The daughters were engaged in various aspects creating knowledge together. As outlined above, a daughter had a voice in developing the interview guide, those who participated in the unstructured focus group interview had the opportunity to lead discussions, and all four participants were invited to review transcripts, subsequent analysis and interpretations in the member checking process.

Ethical approval was obtained for the study in which the participants had the opportunity to pass on a question or withdraw from the study at anytime, without penalty or further question, thus ensuring their dignity was preserved and respect demonstrated. The ethics approval certificate from the Research Ethics Board of the Faculties of Physical Education and Recreation, Agricultural, Life and

Environmental Sciences, and Native Studies appears in Appendix A. The guidelines of the Ethics Board were adhered to at all times throughout this study.

6.7 Sharing Perquisites of Privilege

This final standard for quality in research alludes to the gratitude we owe as qualitative researchers to the people whose lives we portray (Lincoln, 1995). The truth of the matter is we, as researchers, obtain respect, prestige, and economic power in our own worlds due to the people we write about, often denying them the same benefits despite a potential need for such profits (Lincoln, 1995). The participants were each given a copy of the final manuscript. Further, appreciation for their time, thoughts, and words were shown following each point of contact, in a written card to each daughter, in the text of the thesis, as well as in the public defence of the thesis. Finally, participants had the opportunity to connect with each other by way of the focus group interview.

7. RESULTS

The daughters' experiences of play were intertwined with the responsibilities inherent in being a caregiver and the relationships they had with their moms. The three themes and their supporting sub-themes symbolize the heartfelt stories shared by the daughters. The themes were (a) being a good daughter, (b) blurred relationship boundaries, and (c) encumbered play (see Table 2 for all themes).

Being a good daughter meant being available to support their moms with MS and described the caregiving duties for which the daughters took responsibility. The daughters felt mature beyond their years because of the level of caregiving they provided, when they themselves were in need of nurturing. Leaving their moms alone to play outside of their homes was accompanied by guilt and worry that impacted the nature of their leisure and relationships with friends.

Their play experiences lacked spontaneity, as they needed to plan their play around the needs of their mothers. If they did leave their moms at home, these occasions were not free from stress. There was therefore restricted community engagement as a considerable amount of time was spent in the company of their mothers in the context of their own homes to avoid the stress of leaving their moms. As well, the adult-like responsibilities intruded on their time as children. They were able to play at home in the company of their mothers, but only when supporting duties were finished.

Blurred relationship boundaries illustrated the emotional and social

consequences of the daughters' experiences of caregiving for their moms with MS. These daughters felt that, as a result of their caregiving roles, their family dynamics changed and the boundaries between the mother-daughter relationships became blurred.

The daughters' feelings towards their mom's MS and their roles as caregivers required and deserved validation as reflected in how they were or were not supported as caregivers. The daughters also expressed the need to construct identities outside that of caregiver by separating the mother-daughter relationship from the care recipient-caregiver one and spend more time as a daughter, child, or friend.

Encumbered Play portrayed the play context of the daughters in the past and present, and how they have adapted to their circumstances. Some daughters used play to escape their roles as caregiver. A number of the daughters' opportunities for play were supported, while others had less support. However, all were still able to find ways to play, even if it was not their interest. Nevertheless, some daughters still felt they missed out on opportunities to play, and outlined how this has affected their play today.

Table 2

Summary of the Thematic Analysis

Theme	Sub-theme
Being a Good Daughter	Assuming Extra Duties
	Guilt and Worry
	Growing up Quickly
	Delaying Leaving Home
Blurred Relationship Boundaries	Restoring the Daughter Relationship
	Needing Adults to Step In
Encumbered Play	Solitary Play
	Lost Play Opportunities

These daughters of mothers with MS experiences of play will be presented in further detail using the participants' stories to illustrate their meanings.

7.1 Being a Good Daughter

Being good daughters was expressed in several ways. Four sub-themes captured their stories of being a good daughter (a) assuming extra duties, (b) guilt and worry, (c) growing up quickly, and (d) delaying leaving home. The daughters spoke of assuming extra duties beyond that of their peers and the impact it had on their relationships with friends. Their duties as caregivers meant that the

daughters invited their friends to hang out with them at home as they felt guilty and worried about their moms if they were away from home. They also spoke about delaying leaving home until they felt comfortable that their moms had a support network. Each sub-theme will be discussed in turn.

7.1.1 Assuming Extra Duties

The daughters reported they were responsible for duties such as household care (doing laundry, dishes, cleaning bathrooms, buying groceries, cooking, retrieving objects), personal care (helping their mom to the bathroom, helping their mom get dressed, transferring, and giving injections which included waking their mom up at the right time and remembering the location of the last injection site), emotional support (being available to listen) and general support with daily tasks (driving, finances). Carrying out their duties was viewed as part of being a good daughter. Some of these duties they accepted without hesitation, others made them uncomfortable.

Pam considered her duties as being nothing major or “nothing really crazy”, and Elizabeth felt like she was “picking up where [her mom] left off” and that she “owe[d] it to her [mom]” for all the years her mom cared for her. Haley considered her duties as:

Being a daughter...kind of just something that you do because you love your mom and you want to...probably feel like it's your duty to do it.

Pretty much just being...a good daughter. Trying to do what I can to help her.

There were positive aspects of caregiving that the daughters mentioned. All four daughters attested throughout the interviews that caregiving for their moms “brought us closer”, “made us get to know her a lot better”, and helped them to learn “a lot that I would never know otherwise”. Holly learned about hope and optimism in the face of adversity and about “the struggle of just getting around” with a disability. Haley discussed how her caring responsibilities made her “change who I was”. They made her “be a little more caring towards other people” and “more compassionate from what my mom had to go through”.

The daughters acknowledged that they had to take on extra duties beyond that of their peers that pushed the boundaries of what encompassed being a good daughter. These duties often entailed keeping the household running. Elizabeth recalled:

We all have to go to school, we all have to work, but like I feel for myself I have...an extra duty and that...is...making sure my mom's ok, and I know most of my friends wouldn't go out and do the grocery shopping for their household, right, whereas I have to do that.

The daughters' caregiving experiences were framed by what they perceived to be typical duties for children that age. However, they were not sure they had a good understanding of typical responsibilities as Pam and Holly contributed to the running of their households from early on. Pam thought that most eight year-olds were probably not responsible for the entire household's laundry:

Laundry was a big one *I think*, 'cause I don't think a lot of eight year olds

do their own laundry and their mom's laundry and stuff like that, 'cause I had to do a lot of her stuff too, um, I always took care of my room myself, I did all my bed sheets, washed all that stuff, but I think the rest of it, like the cleaning stuff, my mom...got the cleaning lady pretty soon after, so I didn't have to do [that]. I cleaned the bathrooms, that was my thing, I don't know if a lot of kids do that, I don't know. To be honest, I'm not really sure what is like typical or what's not because I was so young.

Although some duties were associated with being a good daughter to their moms, there were some extra tasks they found annoying or uncomfortable. Completing tasks that were considered unnecessary tended to become annoying. Uncomfortable tasks involved medically related interventions and the feelings they evoked.

Holly recalled a story of having friends to her house, which she did often as she needed to be available to her mom. Her mom had a bell that she rung when she required assistance. Holly remembered being interrupted in her play with her friends by the bell and feeling she needed to apologize to her friends. Annoyance at meeting her mom's needs arose when Holly was called by the bell to help with something that she thought her mom did not necessarily need (e.g., a different program on TV). Holly shared:

Lots of times I would have people over and just be watching TV or whatever and I'd hear the bell [my mom would ring when she needed something]...and sometimes it would just drive me crazy, especially being

like “sorry guys, I gotta go upstairs again”, and of course they don’t care, but that was definitely annoying, as a teenager, to have to just [jump] every time she wanted something. And especially if it wasn’t something she really needed. Like I wasn’t a horrible person, if she really had to go to the bathroom or something I wanted to help her, but sometimes it would be just because she wanted something on TV or something more that she didn’t need, and then it would sort of annoy me more.

There were some tasks the daughters could not bring themselves to do for their mothers. Tasks that made the daughters uncomfortable were personal care activities often assumed by nursing personnel such as catheterization and giving of injections. These moms recognized that these tasks were beyond the duties of good daughters and found ways to release them of these tasks. In Holly’s case, her mom timed her injections so that when a visitor came to the house, the visitor could give the injection. Holly recalled:

Lots of the times I would just not do it, if I was really uncomfortable. I had a lot of trouble with needles for awhile, so [my mom would] strategically time it so that someone else, when they were there they could do the needles...and for awhile she needed a catheter, and I was like, “no, I’m not comfortable doing that”, so I was able to sort of step back.

Similarly, Pam’s mom told her that she might have to help with her injections, but perhaps she sensed Pam’s discomfort with the whole process and

“never really asked [Pam] to help her with them”. However, Pam’s discomfort with the caregiving task of assisting with needles went beyond the physical uneasiness that often goes along with a sharp object penetrating human flesh. Needles were a visual reminder that Pam’s mom was actually sick, as there were few external physical reminders of her mom’s MS.

It just really bothered me watching her because...she’s always been kind of good at hiding, or managing her symptoms I suppose...she looks fine, that’s the problem with MS, right, you look totally fine and nobody understands and so sometimes you almost forget that she’s sick and then when she had to inject herself, it’s like “oh wow, she’s really sick”.

7.1.2 Guilt and Worry

If there was no one else at home to offer support, the daughters’ play opportunities were restricted as they did not want to venture far from home in case their moms needed something. Their experiences of play were overshadowed by feelings of guilt and worry.

The daughters felt guilty for leaving their moms at home, especially if they were doing something that they used to do with their moms, such as shopping. Holly stated that feelings of guilt “made it hard to enjoy things” because even when she was out playing with friends, she’d “be worried or feel bad that [she] wasn’t home taking care of her [mom]”. These feelings made it “hard to make the choice to go out some evenings”. Not only did the daughters have self-imposed guilt, but they felt imposed guilt from their moms. Elizabeth recounted, “you just

feel like kind of guilty, like she'll be like "go, go" but really you're thinking she's not thinking that...She's thinking stay at home with me and play cards or watch movies". Further, it was interesting that nothing ever happened while the daughters were away to make them feel guilty, but it was always "what if, what if, what if...I'm not there". The daughters spoke of times when they 'chose' not to leave the house and forgo play opportunities because it was easier to stay home where they did not feel guilty.

Holly played close to home and preferred having friends over to her house. This way she still had the "freedom" to have a social life, but she could also "run upstairs if [her mom] needed anything". Haley indicated that she "didn't really hang out with...friends very much so [she] could be at home a lot more". In the focus group interview, Elizabeth and Holly both shared that they avoided *going out* with friends, and that their friends did not always understand why they 'chose' to stay at home sometimes. Elizabeth recalled:

Even now...it's hard, like you can see, my friends they'll try to take an interest but I don't think they really understand, like, I'll make up excuses why I can't go but really it's because I want to be at home with my mom and I don't want to leave her. (Elizabeth)

And they don't get that, right? (Holly)

No, you can't be like; "I'm going to stay at home and hang out with my mom". (Elizabeth)

Worry was also a prominent experience for these daughters. They described

how they worried about the progression of their mom's MS, worried about the long term effectiveness of the drugs, and worried about relapses. They also worried about what would happen if they were not there to take care of their moms. The feeling of worry was especially prominent for Holly. She recounted: "I didn't do as much because I was always worried and wanting to be at home". She also felt that she had mostly negative memories of her childhood play experiences. She struggled to remember the positives about her past, even though she knew there were many, but mostly she remembered "just being stuck at home all the time and worrying":

Worrying was *huge*. It wasn't necessarily that I was always doing something or not being able to do something, it was the worry. Like even if I was out dancing or doing whatever, I'd be worried. So that's...what I remember.

Holly further explained, when asked if she had the option to stay at home or go out to play, that she technically had a choice, but in reality "there really wasn't because if I went out I'd be so worried that I may as well stay home... 'cause then you're more relaxed and you enjoy yourself anyway. So, yes there was a choice, but no not really". Holly also explained how she would "escape" to play or simply relax whenever her mom had a visitor because "it was the one chance I had to not worry 'cause *somebody* was there".

7.1.3 Growing Up Quickly

Feelings of guilt, worry, and responsibility for the moms all contributed to the daughters' perceptions of maturing faster than their peers. As Holly attested, "it does make you grow up when you're...worried about someone". The daughters discussed paying their mom's bills, accompanying their moms to the doctor, and sitting in on their medical consultations. There was a period when Haley's parents were separated for awhile and "that was probably the biggest boost to grow up...basically I was like an adult". This accelerated maturity created distance between them and their age matched peers. Elizabeth described a routine that was different from what her peers might typically do after school:

Although I have to go to work, I have to go home, do the grocery shopping or take my mom here and *then* go to work, you know what I mean, and...I'm a bit up here where they are down in the lower level and that's where the lack of relation occurs.

The concept of maturity was multi-faceted and had positive and negative outcomes. One daughter expressed how she was "glad" that her mom had MS as it "made me mature faster", where another cited accelerated maturity as not being "fun". A positive aspect of maturing early was expressed as an appreciation for increased understanding of differing life situations. The daughters felt their mom's MS increased their awareness of disability and the struggles people face in life generally. Seeing their moms wrestle with her MS symptoms increased the daughters' sensitivity and empathy toward others with disabilities. Holly used the

metaphor of having her eyes opened to “struggles in general”. Living with her mom’s MS helped her realise that “life sometimes wasn’t always easy”, not just for them, but others too.

The daughters also reported how their responsibilities allowed them to see what was “important in life”. They did not, or perhaps could not afford to, concern themselves with trivial matters that may have occupied their friends’ time. Instead they worried about arguably more important affairs, such as their mom’s MS and the responsibilities involved in keeping a household operating. When Holly was asked why she sometimes felt older than her friends, she replied:

Responsibilities. So like I just, even if it wasn’t caregiving, I just always was aware of being responsible and stuff, whereas lots of my friends didn’t have to even think or worry about that, so that was something that was on my, my mind...it was just more of like what’s important in life type of things and responsibility and maturity.

On the negative side, the daughters described feeling *more* mature than others their own age. These feelings of maturity made it difficult to relate to their peers, due, in part, to having different priorities and knowledge of what was important. Holly, in speaking of her friends, stated that she possessed “that other level of ‘this is more important’ and they didn’t yet”.

The daughters prioritized caregiving for their moms above play or other activities typical of their age. This prioritization was newer for Elizabeth. In our one-on-one interview, she described how much her priorities have changed since

her mom was diagnosed. She illustrated how she was involved in all kinds of sports throughout junior high and high school but stopped playing them so she could spend more time taking care of her mom. Sports were still important to Elizabeth and she would love to get back into them. However, she stated that she “realise[d] what’s *more* important...my mom”.

The reduced ability to relate to peers negatively impacted friendships and leisure activities. Haley conveyed how she “probably felt more mature than a lot of [her] friends” and “definitely started to think some of the stuff [they] did was childish”. She reported “I just didn’t feel like...a high school student, so, didn’t feel like I could act like it”. This perception had a huge impact on Haley’s play network as she “kind of shied away from that a bit more” and eventually moved away and lost touch with her high school friends. Holly nurtured friendships with older girls as a way of addressing her advanced maturity. Holly’s best friend, Christina, was older than her “but never felt older”.

I was lucky that I was friends with Christina who was older because I just sort of felt like I fit in with her friends more because I felt like maybe I didn’t with mine...Well, not necessarily fit in but I would notice that I was different or more mature sometimes.

The daughters added that they tried not to focus on the negative things and be strong for their mom. Pam recalled:

I find that now I’m just, I don’t really focus...on the bad things in life. I know people complain about this, complain about that, and it’s just like, you

know, it could be worse, or you know, something could suddenly happen, like an odd case, and you need to focus on the day and get done what needs to be done and I feel like I have to be more mature about it because I have to be able to support my mom, and if I'm not strong and supportive, then she won't be.

Not only did the daughters feel that they were growing up quickly, other adults also noticed. Haley told a story of the sage advice she received from her mom's friend, Cathy, who also had MS. Cathy helped her realise that she could "still be a teenager" and she didn't "have to be an adult all of a sudden". Haley thought it was good "having someone else that had to deal with [MS]...good in a way to have someone realise that your issues have every reason to be heard". Cathy helped Haley realise that sometimes it needed to "be more about me than about my mom. As much as it made me feel really guilty, it still had to happen".

Haley wanted to encourage other daughters of mothers with MS to strive to still be themselves. She wanted to tell them: "don't try to grow up too fast...try to still be a kid". I asked if caregiving for her mom changed her, and she said in a way it "does change a whole lot of who you are I guess...but you're still you". The advanced responsibilities matured the daughters into the people they became. Haley realized that she didn't want this maturation to happen too quickly by letting go of too much of her childhood too early.

7.1.3 Delaying Leaving Home

In contrast to growing up quickly and maturing beyond their years, the daughters also experienced a delay in their independence. The daughters spoke about how being their mom's caregiver influenced when they felt they would or could move away from home. The daughters did not feel they could move out and become independent until there were alternate support mechanisms in place for their moms. Even upon moving out, the role of caregiving was not far from their consciousness. Haley thought she was being the person her mom needed her to be as she continued to live at home, but through the support of her Mom's friend with MS, discovered that she was not becoming the person she needed to be for herself, or to even know who that person might be. Haley recalled:

I did have to get out and start living my life and couldn't really stay as attached as I was to my mom...you really did need to get out, be yourself, and grow up, you know, be more about you than about your mom.

As Holly, Pam, and Haley no longer lived at home, they were not active caregivers for their moms. Nonetheless, they clearly recalled the events that precipitated their capacity to leave home. Elizabeth at age 19 was still living at home, supporting her mom who was only diagnosed two years earlier. Elizabeth stated that she could not see herself moving out anytime soon, and only if there was someone else there to support her mom. She also said that if she were to move out, it would not be far from her mom and that she would probably be at her mom's all the time anyway. Haley explained that she only moved out when her

mom got back together with her step-dad, otherwise “there’s no way I would have left...definitely would have ended up staying”.

Holly was still living at home at the age of 24. She separated from her role of caregiver when she went overseas for four months. Her mom had to adapt to her absence by reaching out and forming alternative support networks. When Holly returned, her mom’s MS was in remission and she had developed her own social and support networks. For these reasons, Holly felt comfortable enough to move out. It put Holly at ease when her mom was with other people because she knew that someone was there if her mom needed help with something. Before Holly’s trip, her mom only really had Holly to rely on for assistance, but adapted in the absence of her daughter.

7.2 Blurred Relationship Boundaries

Blurred relationship boundaries were described in the subthemes of (a) restoring the daughter relationship, and (b) needing adults to step in.

7.2.1 Restoring the Daughter Relationship

There were times the relationship boundaries became so blurred that the participants actually felt like they were the parent. Holly recounted how her mom “jokes that I’m the mom” and even though this may have been said in jest, it is important to note. Haley felt the same way and recalled:

When my parents were separated we were living in Edmonton and my mom was, can’t remember if she was fully blind or partially blind, but anyways,

when she was blind I was helping her from the bus stop and whatnot, I think, probably the most memorable, it was just kind of silly, and kind of simple things, but it was...kind of almost felt like I was the parent. I think that was probably the most memorable because it was the most eye opening. [It felt] really weird. You don't ever really want to feel like a parent when it's your parent. Your roles are a little reversed. Probably, definitely a little wrong. Weird...I guess, that's about it, just, having to, you know, deal with your parent, when you would kind of be the one being dealt with, so it was a real role reversal.

The daughters spoke at length of desiring more than a care recipient-caregiver relationship with their moms. Haley described the experience of blurred relationship boundaries in her one-on-one interview and how separating from her mom was needed so, "...I can grow up to who I want to be". Given Haley's experiences, I planned to ask the focus group participants (of which Haley was not a member) of the need to separate from the role of caregiver. I did not even need to ask my prepared question.

The discussion about the need for separation in order to construct alternative identities to that of being a caregiver emerged on its own. The daughters in the focus group talked of how their perceived caregiver identity was dominant in their relationships with their mothers and how they needed to spend more time with their moms as daughters rather than caregivers. In order for this to happen, the daughters ultimately had to leave home.

Holly described how a sense of responsibility to her mom would always be present but that it was important that mothers with MS get “support that’s not from her daughter” so that a separation of the care recipient-caregiver and mother-daughter relationships could occur.

I definitely think it can get blurred and it’s gonna be always a balance of...trying to help out as much as you want to and can, but at the same time trying to have your own life and be the daughter and...yeah it for sure gets blurred....My mom wanted us to be so close all the time so I think she liked that relationship, but I really think it’s important for them to get support from someone else because then it allows you to have a separate mother and daughter relationship that’s not based around the disability, and for you to have your own life not based around that. Otherwise, if she’s looking to you for support then it’s going to mess up your whole relationship separate of that...My involvement, it hasn’t had to be much at all lately which is really nice, probably just if something happens. She dislocated her arm not too long ago, so she needed more help then, just driving to places and stuff, but still not every day. One of her home care lives above her, so she has someone to call, which is huge, just to come down if she needed help with something, like washing her hair when she had the [broken] arm, so yeah, it’s really gotten...changed a lot.

It was intriguing that Holly mentioned needing a relationship that was not centred on her mom’s disability. Holly has moved out of her mom’s house and,

with that, has found that her caregiver role is not as dominant as her daughter role. Now when she sees her mom, Holly actually *wants* to talk about her mom's MS. When Holly was living with her mom, her caregiver role was central and she was less interested in hearing about her mom's MS everyday. Now she is glad she is able to see her mom and not have MS-related emotional support intertwined with her mother-daughter relationship on a daily basis. Holly recalled

Now that we've moved past that, I'm older, I've moved out, when we see each other every now and then she'll bring up the disability or whatever, but I'm actually interested and I want to hear about it. When we get together now it's *actually* to just have fun and to catch up and whatever, and yeah, it takes away all that emotional stress. And I mean sometimes it's going to be there, right, like when something important happens and if she has a relapse or whatever, then of course like I'm going to be there for that emotional time, but on a *day-to-day* basis, yeah, that's been a huge transition for sure.

Elizabeth was still struggling to obtain separation of the caregiver and daughter relationship. She talked of wanting to be a daughter first, or wear the daughter "hat" more often and the caregiver hat less. Prior to her mom's diagnosis, Elizabeth and her mom spent leisure time doing mom and daughter things. Over time, Elizabeth's activities with her mom became more focused on managing her mom's MS:

Before she was diagnosed, we would just go driving, right, or just go shopping, go to the dollar store, just silly stuff together, I miss that. You

know, now we can't really do that, it's more if we go out we're going to pick up her meds, or going to a doctor's appointment or you know what I mean? I'd like to wear the daughter hat more just because that's who I'm supposed to be, you know, with the caregiver responsibilities, right?

Pam, like Holly, arrived at the point where she needed to become her own person and distance herself from being her mom's caregiver. Pam realized that if she continued to stay home, her mom would carry on relying on her to the sacrifice of her own growth. With the support of others, Pam was able to transition from being the caregiver for her mom to being more of a daughter to her mom. Pam recollected:

My mom and I are definitely past that and, you know, it did have a lot to do with me moving out on my own because she was turning to me for a lot of things and I didn't want to deal with it, I'm sure I could have handled it but at that time I just didn't *want* to, like you say, I didn't want to hear it from her, I was just like...I want to do my own thing, now like I'm older, ...and, you know, we're really close now and...our lives are separate but I still talk to her every day and...she does have other support networks now aside from just me so then we can have a proper mother and daughter relationship now.

The daughters who were no longer living at home moved past the caregiving role and shifted back to being "mother-daughter". The focus group interview provided Elizabeth, who was still residing at home, with the opportunity

to share her experiences with the other participants. Elizabeth was aware that she was entrenched in the caregiver role by her own doing, her mom's expectation for support, and social pressure to assist her mom. She sought the advice of her physician. He encouraged her to lead her own life, stating that her mom was still very able. He implied that if her mom was encouraged to do things for herself, Elizabeth may be able to pursue things that were of importance to her. Elizabeth shared:

'Cause right now like it feels like I'm not her daughter, more like I'm her caregiver, and that's often what she refers to me as, or like other people will, and of course I'm going to do it for her, right, like after everything she's done for me, but sometimes it would be just like, you know, my daughter, you know, that would be nice, and I've talked to our family doctor, he's really good, and he said, you know, "You need to still live your own life, and your mom is, she's still capable. She's not in a wheelchair or, you know, she's not bed-ridden or anything, she can get up and she can do her own stuff and you need to encourage that so that she's not always relying on you".

7.2.2 Needing Adults to Step In

The daughters wished they had more fluid boundaries between their immediate and extended families. They often did not feel support or understanding from their extended family. The lack of support from extended family may have been due to the fact that the daughters' families were small, or

just that they lacked empathy. Although Holly had support from friends, she did not have “the support from other family” and “not having it from [her] brother and not having it from [her] dad” made her feel like it “was just all [her]”.

Further, Elizabeth commented how the only support provided by her family was from her aunt but even then, “she’s there for my mom, but not really...only if it’s convenient for her”. Elizabeth also commented that her aunt doesn’t ‘get it’ as she’ll “make remarks about my mom”. Elizabeth’s aunt, like others in their lives, have said things like, “she’s fine, it’s not like she’s dying from cancer or anything” or, “oh it’s just MS...whatever”, when in reality, “it’s not whatever, it is a big deal”. Those family members who didn’t understand thought the moms were “playing it up” or made comments about how they wish they “could just sit at home on disability and do nothing”. When Elizabeth shared these stories in the focus group interview, the other daughters and I gasped at the nerve of some people and Pam chided them saying, “you don’t know what our lives have been like...how dare you!”

The daughters relayed that they could have used more support from other adults. During Elizabeth’s one-on-one interview, she became emotional when I asked if she wished there was somebody else that could help: “Yeah...I do, I think it’s important because people really don’t realise...[crying]...how much I have to go through [struggling to get the words out]... ‘Cause it’s hard...She is a burden but she’s not, it’s just sometimes I need help”. Later in the group interview, Elizabeth articulated again how she needed somebody upon whom she could rely:

I think just even having somebody who can come over and maybe like...even take her out...or like play cards with her, 'cause my mom loves that too, or crib or, you know, and like my aunt she'll every so often take her out, but it's more of the pity thing, like, you know, "I feel sorry for you, you can't do this", whereas [I'd prefer if they would] phone her up and just say "Hey...do you wanna go get some coffee or something", so, just somebody who's there.

Holly had also wished for an adult support network for her mom:

All those little helpful, day-to-day, cooking meals, laundry. We had home care but they're only there for a few hours every morning, so what about the rest of the day? So yeah just more ...*adults* to step in... I felt like *I* had a support network, like I had really good friends who I felt comfortable with sharing everything about MS and my mom and they came over all the time, but, my mom had no support network, and so, doing the logistical things, not as a friend, but, no one to do the grocery shopping again, the driving around, the just being there in case something happens so I could go out.

The importance of an adult support network became apparent when Holly discussed her mom's current social activities. Now three nights a week, Holly's mom is with people and Holly is "so much less stressed". She wondered what that would have been like if her mom had that support when she was younger.

Interestingly, when Holly was younger, she didn't think she needed support or to talk to anyone about what *she* was feeling because, as she attested, she was in "caregiver mode" and therefore "into...being the strong one". Nevertheless, Holly was curious how that support would have "affected things".

Whereas Holly felt the support of her friends, Elizabeth did not find solace in her friendships. Holly's friends "knew about my mom's MS" and they also "knew the history", so she didn't have to constantly educate them about MS, which was "really nice". Holly knew her friends "understood" as "they were able to help me help my mom", in addition, "they were able to just have fun and not talk about it when [they were] not helping her". In contrast, Elizabeth indicated that her friends didn't empathize and she found it difficult as she didn't "really have somebody who I could turn to." None of her friends' parents had MS or "any type of health issue" so it constantly left her explaining to people why her mom "couldn't go to some of my games" or "why she had to have a nap every day".

Tied in with lack of support from family and friends was a desire to be acknowledged for all they were doing for their mothers and experiencing as a member of a family living with MS. Their moms were recognized as people living with MS but the impact of MS on other members of the family, and them specifically as caregivers, was not acknowledged. They often felt that it wasn't about what they were going through with MS, "it was more about what she was going through". If the daughters were ever ill, it was "never as bad as her". The daughters all felt that they "never get any recognition for any tough things that

[they're] going through". Elizabeth talked about her feelings toward this lack of acknowledgement during the focus group interview:

People will ask how my mom, how *she* is, right, obviously, but I find that they won't ask how *I'm* doing and that's just kind of tough. I know my mom is having a hard time too, but it's really affecting me as well, and so I think people kind of just neglect that and forget about it.

Pam expressed how she felt that people didn't realise her skills, maturity, sacrifice, or the support she provided her mom and family. Others were unaware of what these daughters have all adapted to, but rather they see them coping and putting on a brave face. The only time Holly felt acknowledged as a person also dealing with MS, "it was more *pity* than actual *help*...it was more like 'oh you poor thing' every now and then...but it wasn't like, 'oh what can we do to make this easier on you'".

7.3 Encumbered Play

Being a good daughter and balancing their caregiver duties with their desire to be a daughter was expressed in how the daughters' experienced play. Their experiences of play were hampered and described through the subthemes of (a) solitary play and (b) lost play opportunities.

Collectively, the daughters expressed the reasons for play to be a way "to get away from everything," "forget about school," and "forget about... troubles with parents or whatever and just have fun". Play was described as making the

best of a difficult situation, an escape from the role of caregiver, lacking in spontaneity, and framed by the support of others.

The activities in which the daughters engaged were probably similar in nature to the activities in which their peers engaged. The context and circumstances however, surrounding when and where the daughters played were unique to their family contexts. Pam listed some activities that she considered to be play, which included “doing some sport activities” “rollerblading” and “bike riding”. Holly liked rollerblading too. She spoke about how she enjoyed it because it was “easy”—not physically but because you don’t need much equipment and you “go when you can”. She also felt play was “anything where it’s just pure enjoyment and you’re not really worried about anything else” and “something you decide to do on your own for fun”. Elizabeth thought play was “enjoyment” “interacting with other people” and “being active...even if it’s...competitive or just recreation”.

Haley did not relate to physical activity play as she has never been “into physical activity”. Rather she defined play as “quiet stuff...reading a book or playing with the dogs” and anything she could do by herself was preferable to groups. Haley did whatever she could to escape, “read a book, watch TV...play video games or whatever, stuff that [she] didn’t have to actually focus on, or concentrate or think about anything else”. For her, play was “peaceful”, a time when she could be herself and when she could get away from her thoughts.

7.3.1 Solitary Play

The daughters' play experiences were marked by recollections of solitary play. Following their moms being diagnosed with MS, Pam mentioned: "I had to start playing by myself," and "learn how to do things on my own". Solitary play may have been punctuated by being only children, having few shared interests with their brothers, or not having sisters living at home. Haley noted that she felt she didn't play very much possibly because she became "more private, more solitary" and "didn't really get out as much" after her mom's MS diagnosis.

When Pam was young, she had a group of kids on the street that she spent many hours playing with each day:

For the most part, when I was really young all of the kids in the neighbourhood, we all were around the same age and we all went to school together, so you know, we'd walk to school together, and...we'd always walk home together, and then go have dinner and come out and play until the streetlights came on, and it was kind of all intertwined when I was really little...we all just hung out until we were called five times to come back in. We would do that every single day.

Pam was seven years old when her mom was diagnosed with MS. Pam shared that her mom's MS allowed her to attend a fine arts school that offered a dance program. This was because her mom was on long term disability leave from her employment and could drive her to and from school each day. Pam recalled, "The one good thing that came out of [MS] is that mom was able to go to that fine arts school, and so that's when I started dancing".

During the times when Pam's mom was not well, however, others stepped forward to provide play opportunities for her. Pam recalled that her mom's friends "came over and played with me sometimes because they had kids themselves and they thought it was...too bad my mom was laying in bed for three months". As well, her step dad's parents not only cooked meals for them, but they also came to "hang out with me, take me to the park and stuff like that". Nobody asked them to help out, "they just...stepped up and did it". Further, Pam went to friends' houses and their moms would play with her. Pam "never went home", as it "was more fun there". She would try to stay at friends' houses as much as she could as she "didn't like being at home", so "going out and playing with my friends was...definitely an escape". She added:

My mom was...always so tired and never wanted to do anything so like I'd go to my friend's house and her mom would play with us and we'd hang out and go to the mall, or, you know, go to the beach.

Pam ended up moving away from her neighbourhood. She remembered "not being as active on that [new] street" and she "pretty much hung out all the time in my room". Not having that group of kids made group and spontaneous free play less accessible to Pam. Pam talked about having to "entertain myself" as "there's always a few hours of the day for sure that my mom wasn't able to do anything" as she had to take naps due to fatigue. Even to this day when Pam is on vacation with her mom, she has to entertain herself for a few hours of the day, and she thought this might be why she enjoys doing things on her own.

Holly was eleven years old when her mom was diagnosed with MS and around this age she played alone or with one really good friend, and she “wasn’t really involved in anything organized and nothing with school”. Holly talked about the shared interest of the “Backstreet Boys” with another girl and how this “brought us together to play a lot”.

Holly, in contrast to the other daughters had play that intertwined with the play activities of another family. Christina’s family, Holly’s girlfriend, included her in their play activities as they recognized that her mom was not able to transport Holly to and from activities. Organized activities that Holly participated in were those that her “friends did” and “it wasn’t ever...what I was interested in”. She joined dance because her friend Christina joined and Christina’s mom offered to drive her there and back. Jazz class was a “such an embarrassment” for Holly that she “definitely didn’t want to go back”:

Whatever I did as play or physical activity was whatever my close friends did because then their parents could drive me. And so, lots of the sports and whatever was individual stuff, I was never on teams, but, my one friend her parents got her into jazz and so I thought, hey, I can actually go out with her, her parents will pick me up and drive me. So I joined jazz, and I was *the* worst dancer in the entire world [all laugh]...but it was just really funny and really interesting that that’s what I ended up doing, you know, nothing that I would have ever chosen or enjoyed, but it’s because it’s what I *could* do.

Not only did Holly dance with her friend Christina, but she also played with her on family holidays as she “went on every family holiday” with Christina’s family. They supported Holly’s holiday play and she remembers family trips not with her own family, “it was with someone else’s”. Holly smiled as she said this, probably because she had good memories of these holidays, but also, I think, because she thought it was unusual that she experienced family holidays with a family other than her own. Christina’s family treated her like one of their own; they let Holly stay with them many times when her mom was in the hospital, and knowing she had “a place to go and another...family at all times really made a huge difference” to Holly, as she didn’t feel “alone” when her mom was sick.

Holly’s support extended to her larger group of friends as well. She recalled how her friends came to understand that she could not be away from home for long periods and they were content to go her house to play. Her friends respected Holly’s need to support her mom and made it easy for Holly to stay connected with them:

Sometimes I’d have people over, I had really good friends that were really good about that, they would just come to my place...they wouldn’t ask if I was uncomfortable doing something else, they would just be fine to come back to my house. [They wouldn’t bug] me to go out places ‘cause I couldn’t and they knew I always wanted to be at home. Probably ‘cause I was worried a lot.

7.3.3 Lost Play Opportunities

The daughters spoke of how they experienced lost play opportunities with their moms and peers following their moms' diagnoses of MS. Pam and Holly referenced life "before MS". Holly's mom said, "I wish you could remember me before MS". Both moms indicated to their daughters that they were active prior to their diagnosis, but neither Pam nor Holly remembered their moms that way. Pam stated that she "didn't get to learn anything from her [mom]" and therefore had no "role model when it came to...physical activity". Holly commented that she "definitely didn't have that [role model] to...look up to or strive for".

Pam remembered how her mom "never went on...field trips" because she could not participate in any day-long activities due to fatigue. Pam thought that because her mom could not participate in her play activities, it limited interactions with her mom. Pam's recollections were mixed. She did not feel she had memories of her mom as a physically active person, and yet, Pam chose her mom's old baseball glove as an artefact, representative of her play experiences with her mom's baseball team. Pam would have been younger than eight years old at the time:

When I was really young, before she was diagnosed, she used to play on her work baseball team and I remember playing with them all the time and having a really good time and using her glove when I could and then I started using it when I got older. I used it for a really long time but after she was diagnosed, no more...baseball games with my mom, no...not a lot of throw and catching kind of stuff, and...I don't know, kind of just

reminds me of good and bad things from growing up with it.

Elizabeth also spoke of her mom's involvement in her "before MS" play experiences. Elizabeth's mom supported her by coming out to watch her games, and was well known by the players and coach. Her mom's support at games meant "everything" to her. It was difficult for Elizabeth when her mom was in the hospital and could no longer be at her games. Elizabeth's felt "alone". It was difficult seeing team mates' parents because "their parents could...just come out" and she wished her own mom could be there. Elizabeth's rugby team even made her mom a card when she was in the hospital. The card was the artefact that Elizabeth brought to the group interview. It had a photo of her rugby team on the front. She relayed:

I was in grade, it was grade 12, so yeah two years ago, and I was playing with my high school rugby team and my mom used to be at every game, every practice, everything. All the girls knew who she was. She went into the hospital, and then my coach got together and actually just made a card for her and everyone signed it, a bunch of my teachers and stuff just 'cause she was so well known and, and they went up to visit her even took her this with a bunch of flowers, so this just really meant a lot...to me and just reminded me of how she couldn't be there but still everyone cared.

The memories of lost play opportunities were especially poignant for Holly—she brought it up on several occasions. She talked about how she did not join sports when her peers were joining and when she did become somewhat

interested later, she did not have the skill level required to become involved, leaving her with a feeling of being left out. It wasn't until later that Holly wished she would have participated:

I don't think I really wanted [to be involved in after school activities] at the time, I think that I just felt like it wasn't me, and it's not something I'd be good at or could do. I just figured I'd sort of missed out, I just missed that opportunity and I didn't want to have to join a team and start from scratch as a beginner, so I don't think I was really upset about it at the time, just because I thought, "I'm just not athletic, I just don't do those things". It wasn't until I got a bit older that I was like, "oh I just should have done it, or I wish I did".

Holly said she didn't participate in many after school activities because her mom couldn't drive her and she "couldn't stay for the after school practices" as she wanted to be at home to support her mom. As Holly got older her sense of being left out became more apparent, because "that's what seems to happen when you go to Junior High and High School", you get involved in extra-curricular activities. She noticed other kids were involved in "stuff after school" and her friends were "always doing something", such as "figure skating" or doing "one thing at least".

In closing, the daughters suggested that their moms' MS influenced their play experiences even today. Pam, Holly, and Haley indicated that they "don't

like group activities” and tend to participate in more “independent things”. In addition to preferring independent activities, they also consider themselves to be less active than they should be. Elizabeth is “not in organised sport anymore” so she can spend more time caregiving for her mom, and for a long time, Pam “didn’t really want to do any sports...I didn’t really care [about them]”. Holly stated that she is not as active as she should be because “that’s the way it’s been forever”, and it is a struggle for her to “*try* and remember to go out and do things”.

8. DISCUSSION

Within the life of a family, unexpected events occur. The families in this study experienced the unexpected event of chronic illness. The participants in this study were confronted with new family relationships that challenged their previous known roles of daughter and mother that shifted overall family patterns (Cox & Paley, 2003). The daughters' stories were alive with resilience in situations where they themselves had no economic or social power to bring about change for their families (Yerby, 1995). The diagnosis of MS resulted in the taken-for-granted assumption that the daughters would assume the role of caregiver for their moms. The daughters' experiences of play were set against the backdrop of their roles as caregivers for their moms and families.

In the literature, young caregivers are defined by exaggerated levels or forms of caring which have a restrictive or negative impact on their childhood (Aldridge & Becker, 1999). The daughters' lives were reflective of young caregivers in the level and form of care they provided. They assumed household duties (grocery shopping, laundry, banking) as well as physical (transfers, personal care) and psychological care of their moms (companionship). As previously reported by Lackey and Gates (2001) personal care tasks were most difficult for the daughters, to the extent that refusal to provide injections and completion of very personal care such as catheterization were reported. The daughters placed boundaries around their caregiving relationship with their moms that were related to their medical care (Turnbull & Turnbull, 1997). For Pam,

injections were also an uncomfortable reminder of her mom's chronic and potentially advancing illness.

Becoming caregivers for their mothers may have been a reflection of little or no extended family subsystem support (Aldridge, 1999). Blended families (step-dads) and moves may have contributed to the loss or distancing of previously established networks, although this was not clearly articulated by the daughters.

8.1 Being a Good Daughter

The families were brought to a transition point in their functioning with the diagnosis of parental MS. Their moms' illnesses were characterized by hospitalizations, loss of sensory and physical functioning, and inability to maintain previous household duties in the home. The families continued to function. The daughters assumed caregiver responsibilities for their moms and household duties for their families. This adaptive self-organization of the family systems created changes in the pattern of interactions within the families at multiple levels (Cox & Paley, 2003). Examples of new family patterns included decreased social networks through loss of employment and illness related decreases in activity, mothers became socially and functionally dependent upon their daughters, daughters assumed household duties previously held by their moms, daughters' networks of friends decreased, and mother and daughter play experiences narrowed in scope. These arguably negative outputs were balanced with the daughters becoming closer to their moms and gaining an increased

sensitivity to the diverse family roles that illness and disability places on families (Yerby, 1995).

On one level, the daughters' experiences could be read as stories of survived childhoods—childhoods that were socially restricted and marked by extraordinary responsibilities. The point of reconstructing the daughters' experiences was not to focus on negative family experiences, concluding that daughters of families with parental MS are “damaged...but bring to light that which may have been kept in the shadows because of shame, fear of judgment, pain, or rejection” (Yerby, 1995, p. 356). In hearing the stories we may be moved to a new level of understanding as our own values of parenting and a play-enriched childhood are confronted.

The daughters experienced pressure to assume caregiving duties because of their own sense of reciprocity for the years that their moms dedicated to their upbringing. They also succumbed to the power exerted by social norms that dictate gender role patterns. Women and female children take over more household and caregiving responsibilities than other family members (Cox & Paley, 2003; Yerby, 1995). The daughters' stories of “escape” from the cycle of being their moms' companions and caregivers and their sacrifice of friendships and play opportunities was evidence of them being locked into their roles. There was a tension between wanting to escape to play and feelings of guilt and worry if they did. They wanted to be “good daughters”, but they also felt remorse for missed play and socialization opportunities. The stories heard were also stories of resiliency and strength as the daughters coped within their new relationships.

The voices of the moms were not part of this study, but their voices are integral to understanding the family unit. I do not want to construct a story that “blames mothers” for family problems or creates an “us versus them stance” to the meanings of the stories shared (Rothbaum, Rosen, Ujiie, & Uchida, 2002; Yerby, 1995). It may have been that the moms felt they were empowering their daughters to assume a significant participatory role in the family. What may be construed as controlling behaviour on the part of the mom may be a coping strategy for lost position in the family, feelings of inadequacy, inability to contribute to the family as she did in the past or fear of being isolated from those she loved. Staying together may also have been the motivation behind the mom’s motivation to ring the bell. Without both voices, however, sense making of the meaning behind the action is difficult. The stories of these families remain incomplete.

In many ways, the daughters’ stories of their responsibilities were not unlike that reported in the caregiving literature. The daughters’ duties are consistent with the caregiving activities that several researchers have previously reported (Dearden & Becker, 1995; Lackey & Gates, 2001; Pakenham et al., 2006). However, they did not mention providing childcare to other siblings which has been reported in the literature (Aldridge & Becker, 1994; Bauman et al., 2006; Dearden & Becker, 2004; Warren, 2007). This omission in their stories was due to their specific family configurations. Two of the four daughters were only children and the others were the youngest in the families. In the reverse, the daughters with older siblings did not mention support from their siblings in their

moms' care of household duties.

Consistent with the published literature, the daughters spoke of being mature for their ages while also wishing that their launch into adult-like responsibilities would have been delayed (De Judicibus & McCabe, 2004). This false maturity created distancing from the interests of their peers and social isolation (Arnaud, 1959). To compensate, the daughters sought social relationships with older friends.

Worry was a prominent experience that emerged in previous 'young caregiver' studies (Packenham et al., 2006) and was also embedded in the experiences of the daughters in this study. Some daughters reported sometimes choosing not to go out with friends to avoid worrying about their moms. Not taking advantage of these opportunities to play with friends negatively impacted the daughters' social well-being through social isolation and reduced leisure activities.

8.2 Blurred Relationship Boundaries

The daughters indicated that their relationships with their moms were blurred by their caregiving duties. The extent of their duties was due in part to the support available from extended family members and other support agencies. The role of caregivers was not truly resolved for the daughters until they left home.

Within family systems theory (Turnbull & Turnbull, 1997) conceptual framework, family subsystems (parental, sibling, extended family, and marital) are separated by boundaries and these boundaries are created by the interaction of

family members with each other and by the family unit in its interactions with outside influences. The boundaries within a family help to define its members' roles with respect to each other. Further, there is a range of cohesion within these subsystems. Cohesion is represented on a continuum with high disengagement on one end and high enmeshment on the other. It refers to family members' emotional bonding with each other and to the level of independence they feel within the family system. According to Turnbull and Turnbull, families are highly cohesive if their boundaries among their subsystems are blurred or weak. Carnes (1981, p. 70-71) uses the metaphor of the touching of hands to describe cohesion in the family:

The dilemma is how to be close yet separate. When the fingers are intertwined, it at first feels secure and warm. Yet when one partner (or family member) tries to move, it is difficult at best. The squeezing pressure may even be painful...The paradox of every relationship is how to touch and yet not hold on.

In the context of this study, the daughters had blurred boundaries and were therefore highly cohesive, in some cases to the point of "enmeshment" (Turnbull and Turnbull, p. 108), or, to use the above metaphor, the hands were gripping each other too tightly and couldn't be separated. For example, enmeshment was revealed when the daughters' felt the tension of wanting to be "good daughters" by supporting their moms, but also wanted to wear the daughter and friend hats more by being free to play without worry.

When the daughters wore their ‘caregiver’ hat, I don’t think they were drawn into the parenting role within the parental subsystem, but rather the mothers were interacting with the daughters as if they were an outside influence (i.e., treating them as formal caregivers). This does not imply the daughters were on the outside of the family unit or that their mothers were treating them as such, but that perhaps the daughters sometimes felt like formal caregivers, and potentially the mothers viewed them in this way as a means of coping.

Stories of the families evolving by tapping into external subsystems were minimal, although advice from outsiders was given to try to avoid both growing up too quickly and helping too much. Outside of one family’s access to home care, other organizational support (input) into the family system were all but absent. Stories of extended family support were also minimal and when in the instance of the aunt providing support to her sister, the motivation for the support was not considered genuine, thereby negating its instrumental value.

The families’ shallow support networks contributed to the daughters’ sense of responsibility. Pakenham and Bursnall (2006) reported that young caregivers felt they had no choice in becoming their parents’ caregiver, and therefore caregiving was their responsibility. Three of the four daughters referred to having little support from their extended family, either due to geographical distance or a lack of understanding. In Elizabeth’s case, her extended family did not understand MS and thought her mom was “playing it up”. Further, they referred to cancer as if it was a more severe or ‘important’ disease, as it can be fatal. They did not offer support to Elizabeth or her mom, as it seemed that MS

was not disabling or overtly disabling enough to warrant such empathy. It would appear that we need to educate family members about MS and its manifestations so they may realise that people with MS are not “playing it up” and experience authentic and debilitating symptoms that impact their quality of life and that of their families. Although MS isn’t necessarily fatal, this fact should not preclude support from family members. According to Turnbull & Turnbull, “there is little research about disability issues and extended family members” (p. 106), and few programs have been developed to support extended family members.

Holly indicated that her mom reinforced her role as caregiver by interrupting her play with friends by ringing a bell for assistance for what were perceived to be non-essential caregiver tasks. The response to this maternal behaviour was a desire to escape from the caregiver relationship. This desire could not be resolved without the family evolving to a new level of self-sufficiency—that being alternate support systems for the family member experiencing the illness. To make sense of the bell ringing behaviour of the mom, we would need to add her stories of family relationships to the dialogue. We all selectively remember life events (Yerby, 1995). The stories that were depicted by the daughters were uncomfortable at times.

The daughters wished to be acknowledged and validated for their contribution to their families both from within and outside their families. Although not stipulated by the daughters, the quality and quantity of their caregiving may have masked the need imposed on other family members by their moms’ illness. They may also have been experiencing the social norm of

‘families looking after their own’ as a self-contained unit (Yerby, 1995). From the outside, the families appeared to be stable, but within, relationships were strained, guilt motivated, maintained through subtle displays of power, and narrowing in their social reach. Only at critical points, such as the removal of a member of the family through hospitalization, did acknowledgement that the family was undergoing change from those outside the family occur. These instances were few in number and described as brief, such as the care from Elizabeth’s rugby team.

Elizabeth’s story of her physician suggesting to her that she should remember that her mom was “still capable” to perform some self-care tasks reflected the circular patterns of family relationships. When Elizabeth was in the role of her mom’s caregiver (Kozlowska & Hanney, 2002), the support she provided may have contributed to her mom doing less for herself than she was perhaps capable of doing. Stated differently, in her role as a caregiver, Elizabeth was affording her mom’s disengagement in some activities she was possibly capable of fulfilling, which may have created a perception in Elizabeth’s mind that she was indispensable (Beavin Bavelas & Segal, 1982).

In the young caregiver literature, the terms “role reversal” and “parentified child” (Barnett & Parker, 1998; Earley & Cushway, 2002) have been used to describe these altered family dynamics. While I understand why these terms might be used, I do not believe them to be appropriate or accurate. As Brody (1990) states, role reversal is a superficial concept when it acts as an explanation of the process that occurs when a parent relies on care from a child. This term

suggests a complete switch of responsibilities and perspectives between parent and child, and does not convey the complexities of the relationship between a mother and her child caregiver. Even if children of parents with MS may take on some responsibilities that might normally be done by adults, this does not mean that they automatically internalise “the concern and sense of responsibility that parents have for their children’s welfare in all its manifestations” (Keith & Morris, 1996, p. 94). These ‘parent-like’ duties may indeed lead to accelerated maturity, however, this is not analogous to parenting their parents.

The second family transition point occurred with the daughters’ decision to leave home. For three of the four families, new patterns emerged as the daughters transitioned away from home and relinquished their caregiving responsibilities to others. The daughters were instrumental in disrupting the caregiver cycles that had developed, without systematic input from outside organizations or external family subsystems.

Once the families had evolved beyond the daughter as caregiver, the daughters renewed their relationships with their moms. There appeared to be a sense of healing on the part of the daughters that enabled them to create a new and authentic relationship with their mothers. The families’ adaptability was quite remarkable. The daughters’ experiences illustrated that positive transformational change is possible in families and that identities do not necessarily have to persist or define family relationships (Yerby, 1995). “Memories can be given new interpretations with time; stories can be reframed and can evolve” (Yerby, 1995, p. 353). Over time there was a positive reframing of family circumstances

(Kozlowska & Hanney, 2002). The third family (Elizabeth's family) was early in its cycle of coping with the circumstances of maternal illness and reflected many of the relationship patterns that the other families had already negotiated.

8.3 Encumbered Play

The level and forms of care the daughters provided for their moms and families impacted the time they had for play. Extracurricular activities and time with friends were carefully managed so that they were accessible to their moms as previously reported by Lackey & Gates (2001). As play allows for the discovery of self (Galligan, 2000), children need separation and distance from their caregiving roles so they may have a relationship with and learn more about themselves. This relationship with the self is worthy of pursuing, as Joseph Campbell quotes, "the privilege of a lifetime is being who you are".

The daughters in this study described how they adapted to their play opportunities given the contexts as caregivers for their moms and families. Play was experienced close to home, was individual in nature (e.g., rollerblading), and occurred less frequently than they would have liked. They also highlighted how their past play experiences have influenced how they play now, and discussed how their mothers play now. Free play is reported to be on the decline for several reasons, one being over-protective parents. Malone (2007) has termed this the "bubble-wrap" (p. 513) generation and posits that parents' fears and subsequent restrictions on their children's activities and independence may, in fact, cause more harm as it can detract from their ability to navigate their environments.

Previous generations were free to walk to school alone or play in the streets, but the changing climate of fear has restricted these movements, leaving children with less social, psychological, cultural, or environmental capacity (Malone). While children of mothers with MS may arguably have more maturity and resiliency given their circumstances, free play was still encumbered following their moms illness given their need to be close to home. Holly and Pam, in particular, were able to experience some spontaneous free play as children, and my fear is that daughters of mothers with MS growing up in this generation may not have these same opportunities given they may bubble-wrapped.

Pam and Holly longed for a play “role model”, as they couldn’t remember their moms as physically active prior to their diagnosis. They felt that they “didn’t get to learn anything from [their moms]” and this negatively influenced their play opportunities. The daughters’ experiences support an association between parental role models and children’s activity levels (e.g., Anderssen & Wold, 1992; Freedson & Evenson, 1991). While some people with MS lead a physically active lifestyle, overall they tend to be less active than the non-disabled population (Lockwood & Lockwood, 1997), which may impose role modelling constraints to play for some families.

When looking back on their childhood, the experience of missing out on play opportunities was salient for these young caregivers. Recent research states that enjoyable participation in activities during childhood and adolescence can result in a “leisure for life” philosophy (Bocarro, Kanters, Casper, & Forrester, 2008, p. 161), and one might infer that negative experiences may well contribute

to the opposite effect. Furthermore, Iso-Ahola et al.'s (1994) Leisure Repertoire Theory proposes that activities that people are good at and regularly participate in compose their leisure repertoire. Thus individuals who develop a broader spectrum of activities during childhood are more likely to continue participation as they enter adulthood, due to a wider leisure repertoire (Bocarro et al., 2008). The stories of the daughters suggest that their impoverished play experiences in childhood carried over into their adult lives as described in their limited play and physical activity pursuits as adults.

Listening to and sharing the stories of the daughters provoked me to think differently about families and families with MS specifically. These families were unique yet contextually grounded in social norms of illness, gender roles, and the autonomy of family units. These families evolved as daughters and moms were drawn together, driven apart, and tension was alleviated.

9. RECOMMENDATIONS

9.1 Recommendations

During the interviews, I asked the daughters for their recommendations and advice for other daughters of mothers with MS, but also what they would say to policy makers if given the opportunity. Following is a list of recommendations that come from the daughters, as well as my conclusions based on the information gathered:

1. If there is no extended family available to support the mothers and daughters, the government needs to “pay home care and respite more so that they do a good job and they can come more.” They need to be available for more hours per week than is currently available, but they also need to be paid more to ensure quality of service. Holly stated that “many of them were...not adequate workers because they weren’t getting paid enough...so even if they were there, I’d be worried.”
2. Daughters of mothers with MS should try their best to educate themselves and “know what’s going on with [their] mom” so they can better understand her. It is also important for them to have someone they can talk to when necessary. However, the children have to be willing to talk to someone for it to be beneficial; they cannot be forced.
3. Children of parents with MS should not be afraid to *ask* for help from other adults. Even if they don’t want to ask, “just suck it up...take their offers, even if it is out of pity”.
4. Get involved in the MS community as it may allow for “a lot more

understanding and a lot more support” as not only the person with MS is involved, but his/her family as well.

5. Mothers with MS need to play too. Having a strong social support network for mothers opens up opportunities for daughters to play with their own friends without worry.
6. The young caregivers research movement has been criticised by some, as Olsen and Parker (1997) purport, it creates “the kind of dependence that does parents and child no good at all” (p. 130), and risks undermining the role of parents. So how do we find a balance between supporting young caregivers, without further subverting the parents with disability? As Banks et al. (2001) suggest children’s needs may be better addressed through services which empower their parents. In this paradigm, the “problem” of young caregivers and children affected by disability is a result of the inequality experienced by people with disabilities in our current society (Banks et al., 2001). Thus, the needs of the parent with a disability must be met, whilst ensuring support is also given to other family members. Olsen (1996) argues that “support for young carers cannot be separated from a consideration of the needs of disabled parents” (p. 51). Meeting the needs of a parent with a disability may be enough support for the children in a particular family, but perhaps in not another. An individualised approach is recommended.
7. While the FST stresses the importance of a whole-family approach, it is also important to keep in mind that children are individuals and should be treated

as such. They should be seen as independent and competent people, not merely engulfed within their family as passive recipients of adult influences (Banks et al., 2001). Future research on children, according to Banks et al. (2001) should consider the following:

Children actively interpret and shape the practices that make up their everyday lives. In particular, it is important for researchers to attend to children's and young people's accounts of their own experiences as valid in their own right. A central ingredient is to question both traditional and new images of children (ranging from troublesome teenagers to young carers), which can distort, oversimplify or deny their personhood (Mayall, 1994; James & Prout, 1998; Christensen & James, 2000). Each child is a whole person, while populations of children are diverse in their characteristics and circumstances, so that it is vital to look beyond simple, single labels. (pp. 802)

8. Daughters of mothers with MS need to be identified as people separate from their moms, dealing with issues separate from their moms. Their voices have every right to be heard along this journey of living with MS, and if they don't, they might remain in their mom's shadow.

For the MS Society:

1. Create a support group where children can go with their mom or dad "so that

kids can see that their mom is like mine...to know that they're not abnormal". Seeing other children in similar situations may help to illuminate the fact that they're "not the only ones".

2. Encourage children to bring a friend to Kids Kamp (a summer camp for teens who have parents with MS). As Holly outlined, "if I think about going to a camp, I would have wanted to bring my best friend...To meet all these...strangers, even though they're kids who [have a parent with MS]...that would make things a little more difficult". It seems logical that for children to be able to share openly about what they might be going through, they would need to feel comfortable in the setting; having a friend with them may increase their comfort. When I contacted the MS Society (Edmonton Chapter), they stated that participants are allowed to bring friends to Kids Kamp. Perhaps this should be advertised more widely.
3. Plan social or recreational outings for kids of parents with MS (the MS Society began doing this beginning winter 2010). While there is Kids Kamp and Teen Escape, this is only once a year and more time commitment than some might be willing to make. As well, it might not be age-appropriate for young adults. It would be a good idea for children to establish relationships with others in similar situations, but in activities not based around their parent's disability.

9.2 Limitations to the Study

There were several limitations to this research study that I would like to

acknowledge in the hope that future researchers are able to learn something from my work. The limitations to the study were as follows:

1. Two of the four daughters' moms had remarried, and therefore were not true lone-parent families. Having support from a step-dad was obviously a very different experience than not having another adult living under the same roof. While these daughters had important information to offer about their play experiences, it would have been good to have daughters from true lone-parent families.
2. I advocate a whole-family perspective, which is why I talked to daughters affected by parental disability. However, it would have been valuable to get other family members' perspectives, including the mothers themselves, as well as extended family members (or anyone who was considered part of the family unit).
3. A maximum variation sampling strategy was employed, which is appropriate for researching MS as it is an extremely variable disease. On the other hand, this strategy resulted in four very diverse experiences, with different support networks, and different play interests and involvement. It led to a wide array of experiences and stories from which to draw central themes, and I was therefore unable to claim data saturation. That being said, I am unsure if you could ever reach data saturation, as people will always have different experiences and stories. The daughters had many similar experiences and appreciated meeting each other to discuss these. I strongly believe that their stories will make a significant contribution to the area of

young caregivers' experiences of play and ways in which disability can affect the whole family.

4. Limiting the study to examining MS had both positives and negatives. It was important not to generalise from one disability to the next, and limiting the study to only families with MS recognises this point. Nevertheless, it would have been interesting to gain perspectives of children of parents with other disabilities, and to see the ways their experiences may have differed from other children and families.
5. The label of "young caregiver" has been criticised as being an adult-imposed term on a childhood experience. I did not impose this term on the daughters, but rather asked them how they define themselves, but none the less, the study was developed based on the "young caregiver" literature.
6. Elizabeth was still in the role of her mother's caregiver. I had stated that it would be ideal for the daughters to be phasing or phased out of their role as caregiver so they could effectively reflect on that experience. As van Manen states, (1997) states, "a person cannot reflect on lived experience while living through the experience" and that "reflection on lived experience is always recollective; it is reflection on experience that is already passed or lived through" (p. 10). However, given that Elizabeth was an adult at the time of her interview, she provided the immediacy involved in her role as caregiver and its impact on her experiences of play.
7. Only three daughters took part in the group interview as the fourth did not feel comfortable doing so. While I respected this wish, it would have been

interesting to have all four perspectives conversing with one another. As well, because artefacts were only brought out at the group interview, I didn't benefit from this expression of her experiences of play while growing up.

8. There was no funding to support this study and I was therefore unable to fly Pam in for the focus group interview. She participated over the phone and thus did not meet the other daughters in person. Non-verbal communication (e.g., body language) between Pam, the other daughters, and myself was lost.
9. There was a period of three to four months in between the one-on-one interviews and the focus group interview, so the daughters' recollection of what was discussed in their one-on-one interview may not have been fresh in their minds.

9.3 Future Directions

Pam, Holly, Elizabeth, and Haley's stories are not representative of all daughters of mothers with MS, but their stories are meaningful and worthy of attention. Beyond them, there are other young caregivers and their families whose voices deserve to be heard, and further insight into their perspectives is required. Future considerations for research are as follows:

1. Future research on children in general, according to Banks et al. (2001), should consider the argument that single labels are inappropriate as children are diverse individuals. The label of "young caregiver" has been criticised as being an identity imposed by adults and not derived from children's own

perspectives. Shakespeare & Watson (1998) have criticised the notion of children as young caregivers because of its imposition of adult theoretical constructs. They propose that ethnographies of children of parents with disability are likely to be more helpful in developing theories based on the way in which children view the world and which therefore have internal validity (Banks et al., 2001).

2. To gain a deeper understanding of the experiences of children with parent(s) with a disability, further exploration in varying contexts is needed. Dearden & Becker (2004), in their report on young carers in the UK, found that the majority of people with care needs were mothers; this was especially true in lone-parent families where mothers accounted for 70% of people needing care. As well, mothers tend to prefer their daughters' support over their sons (Suitor & Pillemer, 2006). Hearing from male caregivers, young caregivers in dual-parent families, caregivers who have siblings, and both male and female caregivers who support their fathers should be explored.
3. To ensure a whole-family approach is taken, getting the perspectives of parents and any other member of the family unit (including extended family, as defined by that family) would be beneficial.
4. Since participant recruitment was difficult, a more sophisticated recruitment process would be recommended for future studies. For example, key people working through the MS Society could be invited to be part of the research study, thereby building a team of researchers who are interested in families experiencing MS.

5. As caregiving is a phenomenon experienced by young people of parents with disabilities, the inclusion criteria could be expanded in future studies. The researcher would have to be cognizant to, of course, keep the individual disability and that family's context in mind throughout, but that was also necessary even when the disability was limited to MS.
6. Holly mentioned that she didn't think she would have asked for help when she was in her role as caregiver as she was in "caregiver mode" and was "into...being the strong one". It would be valuable to conduct a longitudinal study where one interviews young caregivers while still in their roles, as well as reflections when they're older to see how their perspectives may have changed.
7. Family systems theory is grounded in Western ideas. Transferability of the findings to other cultures cannot be assumed. For example, close relationships between child and mother are more common and children experience less adverse effects from such relationships (Rothbaum et al., 2002). System theories have also been critiqued for being formulated at a time when taken-for-granted male value systems defined dysfunctional families and concerns about "mother blaming" arose (Yerby, 1995). As qualitative research is linguistically constructed, recognition of the diversity of modern family configurations and their link to larger social and cultural influences need to be considered. The topic of young caregivers is broad in its implications. Conceptual frameworks such as coping theory and identity theory may bring additional perspectives to research on young caregivers

and their experiences of play.

9.4 Exiting the Field

As Elizabeth became emotional during her one-on-one interview, I followed up with her to outline the support systems available to her through the MS Society. I passed on contact information for the Outreach Coordinator, whose job is to reach out to people affected by MS, which includes family members. Additionally, the Education and Advocacy Coordinator is also a registered Social Worker and said she would be willing to discuss any concerns any participants may have had. Finally, the Vice President, who is also a registered Psychologist, said he was willing to talk to the study participants if they wished. I explained to Elizabeth that these people at the MS Society were made aware of this study and were willing to discuss anything the participants brought forward without cost. I do not know whether Elizabeth took advantage of these resources.

The focus group interview was not only an alternate way to gather data for this project, it was also implemented as a way for the daughters to meet each other, share stories, and, if they wished, to stay in touch with one another. As it turned out, those who partook in the group interview connected with each other stating that it was “neat to hear that other people went through something similar and...had some of the same struggles and issues”. Pam said it was comforting “[to hear] that you guys are out there and you’re so similar.” For Elizabeth the group interview was a “support thing” to get ideas and ask questions of the other daughters who had moms with MS, as her mom’s diagnosis was fairly recent.

They wanted to stay in touch with one another, and asked if I would exchange their e-mail addresses amongst the group. I wonder about the special importance of this network for Elizabeth as she continues to support her mom.

I received an e-mail from Haley after I sent her the Results chapter to review, and she thanked me for including her in the study, which pleased me as she initially showed reluctance to participate. Further, Elizabeth told me that she shared the results section with her mom, which allowed them to have a conversation that might not have otherwise happened; they discussed the ways in which MS had affected not only her mom, but Elizabeth as well. The need to have this discussion with their moms came up in the focus group interview. At that time, it was a conversation that needed to be had, but no one had broached the topic with their moms as it was a difficult one. I am happy to hear that this study was the starting point for that conversation for Elizabeth and her mother.

As a way of recognising the contributions of the daughters, I provided a copy of the thesis to all participants, there was acknowledgement of the participants in the manuscript and defence, and the focus group interview provided a means of linking of the daughters to each other.

I will provide the MS Society with a copy of the thesis, and the staff and members will also be invited to a presentation of this project. It is my sincere hope that the recommendations specific to the MS Society will make a tangible and practical difference in the lives of families living with MS.

9.5 Final Thoughts

The completion of this project has taken me longer than anticipated, but I cannot say I would have done it any differently. Taking a look through a wider lens beyond this thesis, I have had many experiences and been privileged enough to work with inspiring people in my graduate career. I have learned so much from my research and teaching opportunities; lessons that I apply today in my career as the Adapted Physical Education Specialist in Early Learning with the Edmonton Catholic School District. In this capacity, I am fortunate enough to observe four and five year olds at work...at play. When I first started graduate school, I thought play was important, but wasn't sure it would stand as a thesis topic. I knew play was not trivial, but I wasn't sure others would agree. Today, in all that I have learned over the past four years about play, and in all that I learn from the play experts everyday (the children I work with), I can confidently say that the child's right to play must be vehemently defended. No matter the culture, children play, and we must protect this right by encouraging all children to play in whatever way they choose. The following poem by Anita Wadley (1999, p. 50) illustrates the importance of play:

Just Playing

When I'm building in the block room,
Please don't say I'm "Just playing."
For, you see, I'm learning as I play,
About balance, I may be an architect someday.

When I'm getting all dressed up,
Setting the table, caring for the babies,
Don't get the idea I'm "Just Playing."
I may be a mother or a father someday.

When you see me up to my elbows in paint,

Or standing at an easel, or moulding and shaping clay,
 Please don't let me hear you say, "He is Just Playing."
 For, you see, I'm learning as I play.
 I just might be a teacher someday.

When you see me engrossed in a puzzle
 or some "playing" at my school,
 Please don't feel the time is wasted in "play."
 For you see, I'm learning as I play.
 I'm learning to solve problems and concentrate.
 I may be in business someday.

When you see me cooking or tasting foods,
 Please don't think that because I enjoy it, it is "Just Play."
 I'm learning to follow directions and see the differences.
 I may be a cook someday.

When you see me learning to skip, hop, run, and move my body,
 Please don't say I'm "Just Playing."
 For, you see, I'm learning as I play.
 I'm learning how my body works.
 I may be a doctor, nurse, or athlete someday.

When you ask me what I've done at school today,
 And I say, "I just played." Please don't misunderstand me.
 For, you see, I'm learning as I play.
 I'm learning to enjoy and be successful in my work.
 I'm preparing for tomorrow.
 Today, I am a child and my work is play.

Finally, I want to thank my participants – I obviously could not have done this without you! All four of you so generously shared your stories, and I am humbled and honoured you chose to do so. You are all so strong, and such an inspiration of courage to me and I'm sure to other children of mothers with MS. I hope this study was meaningful for you, and that we can keep in touch as we venture further into this area of research. Let's continue to work together to ensure that other daughters of mothers with MS have the "privilege of a lifetime" – to be who they are.

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11. APPENDICES

11.1 APPENDIX A: Ethics Approval Certificate

Notification Re-approval

Date: December 4, 2009
Principal Investigator: Alison Jonzon
Renewal ID: Pro00008677_REN1
Study ID: Pro00008677
Study Title: Daughters of mothers with multiple sclerosis: Their experiences of play
Approval Expiry Date: 13 November 2010

Thank you for returning the request for re-approval of this study. We have reviewed the file on this project for which all documentation is currently up-to-date, and conclude that the proposed research meets the University of Alberta standards for research involving human participants (GFC Policy Section 66). On behalf of the Physical Education and Recreation, Agricultural, Life & Environmental Sciences and Native Studies Research Ethics Board (PER-ALES-NS REB), I am providing a re-approval for the study referenced above.

The expiration date for this approval is noted above. A renewal report or closure report must be submitted next year prior to the expiry of this approval. You will receive electronic reminders at 45, 30, 15 and 1 day(s) prior to the expiry date. If you do not renew on or before that date, you will have to submit a new ethics application.

If there are changes to the project that need to be reviewed, please file an amendment. If any adverse effects to human participants are encountered in your research, please contact the undersigned immediately.

Sincerely,

Wendy Rodgers,
Chair, Physical Education and Recreation (PER), Agricultural Life & Environmental Sciences (ALES) and Native Studies (NS)

Note: This correspondence includes an electronic signature (validation and approval via an online system).

11.2 APPENDIX B: Participant Information Letter

Dear Participant:

This letter is to invite you to participate in a research study titled, “Daughters of Mothers with Multiple Sclerosis: Their Experiences of Play”. My name is Ali Jonzon and I am a graduate student in the Faculty of Physical Education and Recreation at the University of Alberta. I am conducting this study and would be grateful if you could take a few minutes to read this letter and consider participating. The choice to participate in the study is entirely up to you. I will be very happy to answer any questions that you might have.

Background and Purpose

Multiple Sclerosis (MS) is a young person’s disease, with most diagnoses occurring between the ages of 15 and 40; a range which includes prime parenting years. When a mother has MS, the impact is felt by her family too. Children who cared for their mothers with MS may have had unique play experiences while growing up. As play is vital for optimal health and well-being of children, it is that important we understand more about these experiences.

The purpose of the study is to understand how *daughters of mothers with MS experience play*. This study will help us to:

- (1) better understand daughters of mothers with MS experiences of play from their perspective; and
- (2) learn more about the daughters' support network and how this influences their play experiences.

Associate Professor Dr. Donna Goodwin will supervise the study. The information gathered by this study will be used to gain further knowledge in this area and may be published in a journal or presented at a conference.

What will the study involve?

You will be asked to participate in a one-on-one interview and one group interview. Each interview will last approximately 1 hour. The total time required of you for the study will be no more than 3 hours. During the interviews, notes will be taken of things that are said and observed. These notes will help us to remember events later on. Your interview will be taped so that none of your important information is forgotten. Your taped words will be written out word-for-word and you will have the opportunity to check that the written words are right and correctly reflect our talk. Only the project members and I will know what you said. We will not share your information with others, including your family members or partners. During the focus group interview, you will be asked to identify an image or artefact that represents your thoughts, feelings, and ideas around your experience of play growing up caring for your mother with MS. We may then take a photocopy or photograph of this image for our analysis. At no time will the photograph be used for financial gain.

Potential Benefits

You will have the opportunity to participate in a university research study and to share your thoughts and experiences about growing up caring for your mother with MS. This information will help us to learn about the experience from an insider perspective, which is very important and may shed light on any further support that young carers may need.

Potential Risks

There are no health risks involved. Participation in this study is entirely voluntary. If you feel uneasy or concerned about answering specific questions, you can simply say 'pass' and I will move to the next question. If I notice that you are uncomfortable with a certain topic or question, I will immediately ask a different question or change the topic of discussion.

Privacy

All information will be kept private. The tapes and notes from the interviews will be identified by a code number and will be kept in a locked filing cabinet to which only the research team will have access. Your name will not appear on the audiotapes and notes, and identifying information will not be written anywhere near the tape or case record. Fake names will be switched for all names that appear in the interview and material for publication. The master sheet identifying names and code numbers will be stored separately. Only members of the research team will review the information. You will not be identified in any presentation or publication of this study. The tapes and notes will be kept for a period of five years post-publication, after which they will be destroyed.

I will protect the privacy of the group discussion, but cannot promise that other contributors will do so. Please respect the privacy of the others by not revealing the contents of the discussion outside the group. However, be aware that others may not respect your privacy.

The information collected may be presented as themes that emerge from the interviews and other gathered information. Quotes will be used to explain the themes, however, privacy of the participants will be a priority at all times. Every effort will be made to protect your identity. All names and other markers will be removed from the quotes.

Right to Withdraw

You will be reminded at the beginning of the interview that you have the right to refuse to answer any of the questions. You may ask to have the tape recorder switched off at any time during the interview. You may withdraw from the study for any reason, at any time, without penalty of any sort. If you withdraw from the study, any data that you have added will be destroyed.

Questions

If you have any questions about the study, please feel free to ask at any point. You are also free to contact me at (780) 492-2679 if you have questions at a later time. If you have concerns about this study, you may contact Dr. Wendy Rodgers who is the Chair of the Faculty Research Ethics Board, at (780) 492-2677. Dr. Rodgers has no direct participation with this study.

Thank you for your considering this research project.

Sincerely,

Ali Jonzon
Graduate Student
Faculty of Physical Education and Recreation

11.3 APPENDIX C: Young Carers of Parents Inventory (YCOPI)

YOUNG CARERS OF PARENTS INVENTORY (YCOPI)

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Queensland Australia

PART A

Please rate each statement below regarding how much you agree with it in terms of your family.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. I feel safe at home	0	1	2	3	4
2. People who have an illness/disability visit our home	0	1	2	3	4
3. My family is just like other families	0	1	2	3	4
4. I worry about my parent(s)	0	1	2	3	4
5. I always wonder if my parent(s) is/are safe	0	1	2	3	4
6. I worry about what will happen to my parent(s)	0	1	2	3	4
7. I take on more responsibility around the house than other people my age	0	1	2	3	4
8. I know more about looking after a household than other people my age	0	1	2	3	4
9. I feel more like an adult than other people my age	0	1	2	3	4
10. I am more grown-up and mature than other people my age	0	1	2	3	4
11. Helping my parent(s) stops me from doing a lot of the things that I want to do	0	1	2	3	4
12. I miss out on a lot of activities because of my home responsibilities	0	1	2	3	4

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
13.I feel as though I am missing out on things that other people my age are doing	0	1	2	3	4
14.I have a lot of time to do the things that I want to do	0	1	2	3	4
15.I wish that I had other people to talk to about my feelings and worries	0	1	2	3	4
16.I sometimes feel alone	0	1	2	3	4
17.Other people do not understand me and my situation	0	1	2	3	4
18.I sometimes miss school/work because I have to help my parent(s)	0	1	2	3	4
19.Because of helping my parent(s) I sometimes feel too tired or too busy to do my study/work	0	1	2	3	4
20. I sometimes feel tired at school/work because I have been helping my parent(s)	0	1	2	3	4
21. Helping my parent(s) stops me from doing paid work	0	1	2	3	4
22. If I do not take on extra responsibilities the house will fall apart	0	1	2	3	4
23. The health of my parent(s) depends a lot on me	0	1	2	3	4
24. I need to be close to my parent(s) in case something happens to them	0	1	2	3	4
25. I just feel like I have to help my parent(s) more than other people my age	0	1	2	3	4
26. Others expect me to help my parent(s)	0	1	2	3	4
27. My parent(s) expects me to help care for them	0	1	2	3	4

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
28. My parent(s) relies on me to help them with house-hold chores	0	1	2	3	4
29. My parent(s) relies on me to help with their personal care (such as showering, dressing, etc)	0	1	2	3	4
30. My parent(s) relies on me to do the shopping and budgeting	0	1	2	3	4
31. I have to look after my other family members	0	1	2	3	4
32. My parent(s) relies on me for emotional support (such as making them feel better)	0	1	2	3	4
33. My parent(s) relies on me to make sure our family is organised	0	1	2	3	4

Do you have a parent who has one of the following conditions?

- **Illness (E.g., cancer)**
- **Intellectual disability**
- **Physical disability (E.g., uses a wheel chair)**
- **Alcohol/drug problem**
- **Mental illness (E.g., depression)?**

1) Yes

2) No

If “Yes” - Please continue and answer the following questions.

If “No” – Please stop answering questions here. Thank you for your participation. We appreciate your time. Please check to make sure you have answered all questions.

YOUNG CARERS OF PARENTS INVENTORY (YCOPI)

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Queensland Australia

PART B

This part of the questionnaire inquires about your experience regarding helping your parent who has a disability/illness.

Which parent has an illness/disability (Please circle)?

- 1) Mother 2) Father 3) Both

If you circled “**Both**”, please answer the rest of the questions regarding the parent with the more severe illness/disability, whom we will refer to as “*parent*”.

For the rest of the questionnaire, we will only be asking you about this “*parent*”.

Please circle each statement below regarding the extent to which you agree with it in terms of your experience of helping your *parent*.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1. I wish that someone else could care for my <i>parent</i>	0	1	2	3	4
2. I wish that I did not have to help my <i>parent</i> as much as I do	0	1	2	3	4
3. I am good at helping my <i>parent</i> and I always know what to do and how to help	0	1	2	3	4
4. I like bringing my friends home	0	1	2	3	4
5. I find it hard explaining to my friends that my <i>parent</i> has an illness/disability	0	1	2	3	4

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
6. I feel embarrassed about my <i>parent's</i> illness/disability	0	1	2	3	4
7. I feel guilty when I go out and have fun	0	1	2	3	4
8. When I am out with friends I feel that I should be at home instead	0	1	2	3	4
9. I feel guilty when I don't help out at home	0	1	2	3	4
10. I do not talk to my family about my concerns regarding my <i>parent</i> because I do not want to upset them	0	1	2	3	4
11. I find it difficult to ask other people for help with my caring role when I need it	0	1	2	3	4
12. I wish that I could talk to other people my age that also have a parent with an illness/disability	0	1	2	3	4
13. I wish that I had more information about my <i>parent's</i> illness/disability	0	1	2	3	4
14. I know exactly what to do to help my <i>parent</i>	0	1	2	3	4
15. I am included in making decisions about my <i>parent's</i> illness/disability	0	1	2	3	4

YCOPI – Part A Subscales	Factors				
	1	2	3	4	5
<i>1 Caregiving responsibilities</i>					
33 My parent(s) relies on me to make sure our family is organised	4				
32 My parent(s) relies on me for emotional support	4				
28 My parent(s) relies on me to help them with household chores	4				
31 I have to look after my other family members	0				
27 My parent(s) expects me to help care for them	2				
30 My parent(s) relies on me to do the shopping and budgeting	4				
26 Others expect me to help my parent(s)	4				
22 If I do not take on extra responsibilities the house will fall apart	2				
<i>2 Perceived maturity</i>					
9 I feel more like an adult than other people my age		0			
10 I am more grown up and mature than others my age		0			
7 I take on more responsibility around the house than others my age		2			
8 I know more about looking after a household than others my age		0			
<i>3 Worry about parents</i>					
6 I worry about what will happen to my parent(s)			4		
5 I always wonder if my parent(s) is/are safe			4		
4 I worry about my parent(s)			4		
<i>4 Activity restrictions</i>					
12 I miss out on activities because of my home responsibilities				2	
11 Helping my parent(s) stops me from doing a lot of things				2	
13 I feel as though I am missing out on things				4	
19 Because of helping my parent(s) I sometimes feel too tired				2	
14 I have a lot of time to do the things that I want to do (reverse score)				2	
20 I sometimes feel tired at school/work because I have been				2	

18 I sometimes miss school/work because I have to help my				2	
21 Helping my parent(s) stops me from doing paid work				0	
5 Isolation					
16 I sometimes feel alone					4
15 I wish that I had other people to talk to about my feelings					4
17 Other people do not understand me and my situation					4
Total Sum	24	2	12	16	12
Total Mean	3.0	0.5	4.0	2.0	4.0
Norm Mean (Mixed young carers)	1.66	2.44	2.90	1.29	2.12
Norm Mean (MS young carers)	1.33	2.26	2.84	1.07	2.00

YCOPI – Part B Subscales	Factors		
	1	2	3
1 Caregiving compulsion			
8 When I am out with friends I feel that I should be home instead	2		
7 I feel guilty when I go out and have fun	2		
10 I do not talk to my family about my concerns regarding my parent because I do not want to upset them	4		
9 I feel guilty when I don't help out at home	4		
11 I find it difficult to ask other people for help with my caring role when I need it	4		
2 Caregiving discomfort			
1 I wish that someone else could care for my parent		4	
2 I wish that I did not have to help my parent as much as I do		4	
6 I feel embarrassed about my parent's illness/disability		2	
*4 I like bringing my friends home		4	
5 I find it hard explaining to my friends that my parent has an illness/disability		4	
3 Caregiving confidence			
14 I know exactly what to do to help my parent			0
3 I am good at helping my parent & I always know what to do & how to help			0
15 I am included in making decisions about my parent(s) illness/disability			0
Total Sum	16	18	0
Total Mean	3.20	3.60	0
Norm Mean (Mixed young carers)	1.88	2.01	1.40
Norm Mean (MS young carers)	1.78	1.23	2.00

* reverse score item

11.3 APPENDIX D: Demographic Information Form

Demographic Information Form

Date of interview: _____

Contact Information

Name: _____

Address: _____

Postal Code: _____

Phone: _____ Email: _____

Date of Birth: _____ Age: _____

Information About Mother's Multiple Sclerosis

Type of MS? _____

Year of Diagnosis? _____

Has your Mother ever used a mobility device(s)? Y N

If so, what type and when (what year(s))? _____

What are some typical symptoms your mom experiences? _____

_____**Personal Information**

Do you currently live in a:

House _____ Apartment _____ Condo _____ Other: _____

Do you live alone, or with others? _____

If with others, with whom? _____

If you have moved out of your Mom's house, what year was it? _____

What is your current relationship status?

Married/common law _____ Single _____ Other? _____

What is your ethnic background? _____

What level of education have you currently obtained?

Junior High _____ High School _____ Post Secondary _____

Are you currently attending school? Y N

If YES, Full Time _____ Part Time _____

If YES, what are you studying? _____

Are you currently working? Y N

If YES, what is your occupation? _____

How many hours do you work per week? (Please circle)

0-10 11-20 21-30 31-40 40+

Family/Friend Information

Do you have any siblings? Y N

If YES, how many brothers? _____ What are their ages? _____

If YES, how many sisters? _____ What are their ages? _____

How long have your parents been separated/divorced? _____

Physical Activity Interests

Are you currently physically active? Y N

If YES, how often do you typically participate in physical activity?

Daily ____ Weekly ____ Monthly ____ Seasonally ____

If applicable, what type(s) of physical activity do you participate in? _____

Is your mother physically active? Y N

Daily ____ Weekly ____ Monthly ____ Seasonally ____

If YES, what type(s) of physical activity does she participate in? _____

11.4 APPENDIX E: Interview Guide

1. Describe a typical day in your childhood.
 - a. After school? On the weekend?
2. Tell me about a time (story/ies) when caregiving became an issue for you.
 - a. What does it mean to you to be a caregiver?
 - i. Positives
 - ii. Negatives
 - b. What makes it easier? More difficult?
 - c. Did it change your family dynamic? How?
 - d. How has it influenced the memory of your childhood?
 - e. How has it influenced your play experiences?
3. How do you define play? Can you describe a particular play experience that you had?
 - a. When you think about the activity of play, what does it mean to you? Represent?
 - b. What are some of the words you associate with play?
 - c. What emotions come to mind when you think of play?
 - d. Favourite activities? Why?
4. Tell me about your play experiences as a child growing up.
 - a. How has your mom's MS had an influence on your play experiences?
 - i. In what way?
 - ii. Can you explain a specific moment or situation?
 - b. How did you experience play activities with your family? With your mom?
 - i. What's one activity that sticks out in your mind that represents a family play activity?
 - c. How did your sibling(s) influence your play experiences? (if applicable)
5. Tell me about your friends/social networks.
 - a. How does this influence your play experiences? Describe your play experiences with friends.
 - b. Is it different from play with your mother? In what way? Can you describe a specific time when you experienced this?
6. What was your support network like?
 - a. Family? Friends? Professional support?
 - b. Did your support network influence your play experiences/habits?
 - c. Have there been other people in your life who influenced your experiences of play? How? (support or limit?)

7. Have your past play experiences influenced your life now?
 - a. Is there a connection between your experiences now and in the past?
 - b. Do you think your past has influenced your present?
 - i. In what way?
 - ii. Could you give an example? A story? A situation?