THE PSYCHOSOCIAL EXPERIENCES OF INDIVIDUALS DIAGNOSED WITH EARLY-ONSET MS

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B.A., University of Saskatchewan, 2002

A Thesis
Submitted to the School of Graduate Studies
of the University of Lethbridge
in Partial Fulfillment of the
Requirements for the Degree

MASTER OF EDUCATION

FACULTY OF EDUCATION

LETHBRIDGE, ALBERTA

July 2005

Abstract

This qualitative study explored the psychosocial experiences of children and adolescents

with early-onset multiple sclerosis. In particular, an emphasis was placed on examining

peer relationships and social behaviours in relation to these experiences. MS is a chronic

neurological disease primarily affecting young adults. However, a proportion of MS

patients have onset during childhood and adolescence. Very little is known about the

psychosocial impact of MS on these children and adolescents. In particular, youth with

MS may be at risk for negative peer experiences due to their chronic illness. Previous

research suggested that negative peer experiences increase the risk of poor psychosocial

development. In addition, research suggested that the social behaviours of these youth

also impact the nature of their experiences with peers. Ultimately, this research aimed to

provide insight into the psychosocial experiences of youth with MS and the role of their

peer relationships. Six linked parent-youth pairs, from the MS Clinic in Calgary, AB,

participated in semi-structured interviews to identify the issues that are pertinent to the

participants' own experiences. Constant comparison analysis was then used to summarize

the range of psychosocial experiences in the adolescent participants. Data analysis was

derived from grounded theory, which provided a framework for examining and

categorizing interview data into themes. The categories were then constructed logically

and systematically into a theoretical model which represented the data. Through this

innovative grounded theory, a theoretical paradigm for understanding the psychosocial

experiences of adolescents with MS was developed. The theory was comprised of two

core categories: "the grief experience" and "dynamic relationships", each with several

sub-categories. There were two primary conclusions drawn from the theory. The first

reflected the significance of grief in understanding psychosocial experiences in

adolescents with MS. The second identified that peer relationships play a variety of roles

in this grief process. The results of this study have many implications for the role of

counsellors in the treatment of adolescents with MS. This model can act as a foundation

for guiding therapeutic treatment and promoting future research in the area of

psychosocial development in children and adolescents with early-onset MS.

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CHAPTER 1: INTRODUCTION

Multiple sclerosis (MS), a chronic, neurological disease, has primarily been understood to develop in early adulthood. However, it is becoming increasingly apparent that the onset of the disease may occur much earlier for a small proportion of those afflicted. Though the population is small, it is apparent that children and adolescents are also at risk of developing MS. Consequently, it is important to identify treatments for this unique group of adolescents. Like any chronic illness, there are physical factors that need to be addressed by medical professionals. However, there are also psychosocial factors that are impacted both directly and indirectly by the MS. These factors are often overlooked by physicians. Therefore, there is a need within the healthcare community to include counsellors in the treatment of these young individuals. A collaborative approach in healthcare allows for the treatment of the entire individual, and not just the disease. Unfortunately, very little is known about the psychosocial impact that a diagnosis of MS may have on children and adolescents. Therefore, research is needed to increase understanding of the emotional and social needs of children and adolescents with MS, and to develop appropriate resources to meet those needs. The specific focus of this study was to explore the nature of peer relationships and social behaviours in the psychosocial development of children and adolescents diagnosed with early-onset MS.

Multiple Sclerosis as a Chronic Neurological Disease

Multiple sclerosis is an unpredictable, and at times disabling, disease of the central nervous system. MS attacks the protective myelin covering of the central nervous system, causing inflammation and often destroying the myelin in patches. The nervous system is responsible for how individuals think, feel, and move. As such, damage to a

particular area in the nervous system can interfere with, or result in loss of, functioning in any of these domains (i.e., cognitive, emotional, physical). Symptoms of MS generally begin occurring in individuals between the ages of 20 and 40 years (e.g., Multiple Sclerosis Society of Canada, 2004; O'Connor, 2002).

With improved diagnostic techniques and greater awareness that multiple sclerosis can strike individuals of any age, more children and adolescents are being diagnosed with the disease. Even though the incidence of MS in youth is rare in comparison to the incidence rate of MS in adults, its existence and prevalence rates are becoming well documented (e.g., Ghezzi et al., 1997). However, many of these individuals are not actually diagnosed until adulthood.

Children and adolescents diagnosed with multiple sclerosis face many of the same hardships as adults diagnosed with the disease. That is, they experience the same neurologically-based symptoms which impact the day-to-day functioning of the individual. However, children and adolescents diagnosed with MS face some unique challenges. Not only do these individuals have to face the same developmental tasks and challenges as healthy children and adolescents, but they now must learn to cope with the extra complication of a chronic illness.

Psychosocial Implications of Multiple Sclerosis

Multiple sclerosis can impact an individual's psychosocial wellbeing (e.g., Banwell, 2004; Kalb, et al., 1999; Rao et al., 1991), in addition to the neurologically based symptoms. For the purpose of this discussion, psychosocial wellbeing is defined as one's behavioural, emotional, and social wellbeing. Some of this impact may be a secondary effect of a neurological symptom. For example, an individual may have to quit

his or her job because he or she is no longer physically or mentally able to do it. However, the manner in which an individual copes with the disease can also greatly impact one's psychosocial wellbeing. For instance some individuals with MS may isolate themselves from others, experience mood swings, or feel depressed. In addition, how others respond to the individual with MS can also impact the individual's psychosocial wellbeing. For example, an individual may be isolated or rejected by others because of the negative impact of the disease on the individual or the demand of their increased physical need.

Just as in adults, MS has an impact on the emotional and social wellbeing of young individuals who suffer from the condition (e.g. Banwell, 2004; Kalb et al., 1999). Children and adolescents may feel increased insecurities about their bodies because of the unpredictable nature of the disease, never quite knowing how their bodies will respond from moment to moment. They may also be at risk for depression and mood-swings. In addition, MS may interfere with the ability of these children and adolescents to participate in activities with their peers. For example, they are more likely to have to sit out of physical activities with their peers due to the impact of MS on their physical functioning. Trying to get one's peers to understand the complexities of MS can be an added challenge to peer relationships. Children and adolescents with a chronic illness may be at higher risk of being isolated by peers (e.g., Palmer, Erickson, Shaffer, Koopman, Amylon, & Steiner, 2000). Therefore, in order for a child or adolescent with MS to maintain an acceptable quality of life, it is important to obtain treatment for both the physical symptoms and the psychosocial factors. One way to address the psychosocial

factors in MS is to involve counsellors in the treatment and diagnostic protocol of these children and adolescents.

<div align="center">A Role for Counsellors</div>

Recently, it has been argued that there is a need for multidisciplinary approaches to healthcare, including social, environmental, and behavioural factors that may jeopardize health, in order to address the entire wellbeing of an individual (Fuemmeler, 2004; World Health Organization, 2001, as cited in Farmer, Clark, & Marien, 2003). Combining effective traditional medical care with counselling and other support programs may better equip healthcare professionals to address the overall wellbeing of an individual with MS. The psychosocial factors often need to be treated through means which are different from those for the physical symptoms (e.g., therapy, support group programs). Therefore, it is necessary to explore what other services might be effective in reducing the impact of a chronic illness on a child or adolescent's functioning (Pless & Nolan, 1991).

Counsellors and psychologists make up a critical part of an interdisciplinary treatment group. While physical symptoms can be addressed by family physicians, neurologists, and other specialists, the psychological team is better equipped to address any difficulties a patient has with psychosocial adjustment. Counsellors can make many positive contributions to the medical team: they can offer consultation and support to staff; they can see the family with members of the medical team to establish collaborative and shared goals for treatment, as well as provide therapeutic interventions to young people and their families (e.g., Drotar, 2002; Feummeler, 2004). However, the main area where the discipline should be able to offer a unique input is in direct therapeutic

interventions to improve the health, happiness and potential for achievement of affected children (Elander & Midence, 1997). A range of therapeutic interventions (e.g., psychodynamic, cognitive-behavioural, behavioural) can be offered to young people with emotional and/or behavioural difficulties. Before effective service can be provided, though, proper assessment of the needs of children and adolescents with early-onset MS must be conducted. One way to assess the needs of this population is through research. Research is very limited in addressing the psychosocial factors impacted by those diagnosed with early-onset MS. As such, treatment and resources addressing this component are almost nonexistent. It is necessary for research, such as this study, to identify ways in which psychological services could contribute to the psychosocial wellbeing for children and adolescents with early-onset MS.

A Call for Research

To date, there is very little research addressing the specific psychosocial implications of multiple sclerosis for children and adolescents with the disease. Significantly more research addresses the psychosocial wellbeing of adults with MS; however the difference in developmental stages between adulthood and childhood or adolescence impacts its applicability. Theorists have argued that late childhood through adolescence is a critical time in social and emotional development (e.g., Erikson, 1968). It is during this time that they are really beginning to grasp the rules of social interactions and develop effective social skills. It is also a time of personal identity development and emotional growth. As such, any negative impact a chronic illness like MS may have on these areas of development increases the threat to the individual's psychosocial

wellbeing. In order to fill this gap in research, the primary goal of this research was to explore the psychosocial experiences of individuals with early-onset MS.

The first sub-objective of the present research was to identify the nature of experiences individuals with early-onset MS have with their peers. Of particular importance to psychosocial development are healthy peer relationships. Social support from peers can have a great impact on the child or adolescent's ability to adjust to and cope with MS. Feeling accepted and supported by peers may make it easier for the individual with MS to accept the changes experienced within his or herself. Peer support is also helpful for managing the day to day symptoms when extra assistance may be needed. However, research has suggested that children and adolescents with chronic illnesses are actually at increased risk for negative peer experiences (Kef, Hox, & Habekothe, 2000; La Greca, 1990). Individuals with early-onset MS may be teased because of their symptoms, or rejected because of their inability to participate in peer social activities (e.g., because of physical limitations or fatigue). These negative peer experiences can result in the individual feeling rejected, isolated, lonely, and depressed. It is evident that positive peer relationships are critical in psychosocial wellbeing, and that negative peer relationships increase the risk for poor psychosocial wellbeing in children and adolescents with early-onset MS.

The second sub-objective of the present research was to study the social behaviours of children and adolescents with early-onset MS as contributors to perceived peer acceptance. Peer relationships are a two-way street: that is, both the individual with MS and the peer have an impact on whether or not the relationship experience is positive or negative. Previous research suggested that children and adolescents with chronic

illnesses are more likely to demonstrate negative social behaviours with their peers (e.g.,

Phipps & Steele, 2002; Thies, 1999). Subsequently, these negative behaviours increase

the risk that the child or adolescent will experience negative peer relationships. Very little

research has addressed the impact of the social skills of children and adolescents with

chronic illnesses on their peer relationships. As these social skills are important

components to peer interactions, it is necessary to also take these behaviours into

consideration when evaluating the nature of peer relationships.

In summary, this thesis attempted to identify the experiences of children and

adolescents with MS. A specific focus was placed on the role of peer relationships and

social behaviours in the psychosocial development of children and adolescents with

early-onset MS. "Identifying children who have social skills deficits or who are having

some difficulty being accepted by peers is a first step in understanding whether

intervention is necessary" (Nabors & Lehmkuhl, 2004). It is important to identify the

factors which impact the psychosocial development of these individuals in order for

adequate and appropriate interventions and services to be developed. Counsellors can

then collaborate with others in the healthcare community to promote the overall

wellbeing of youth with multiple sclerosis. The perceptions of youth with MS and their

parents, from the Calgary, Alberta area, were used to develop an awareness of the

experiences of this population. Interviews were analyzed using grounded theory

methodology. The primary research goal was:

1. To explore the psychosocial experiences of individuals with early-onset MS.

The two secondary research goals were:

1. To identify the nature of experiences that individuals with early-onset MS have with their peers; and

2. To study the social behaviours of children and adolescents with early-onset MS as contributors to perceived peer acceptance.

This chapter provided an introduction to the role of peer relationships in the psychosocial development of children and adolescents diagnosed with early-onset MS, and the need for counselling interventions to address the individual's entire wellbeing. Chapter Two provides a review of the literature related to this topic. Chapter Three addresses the methods, which include a description of grounded theory, participants, measures, procedure, data collection, and methods of data analysis. Chapter Four presents the results of this research. Chapter Five elaborates on the results by discussing the contributions they make to the current literature. Chapter Six concludes with a discussion of the implications of the research for counsellors and future research.

CHAPTER 2: LITERATURE REVIEW

The diagnosis of early-onset multiple sclerosis in childhood and adolescence

brings with it potential threats to the individuals' psychosocial development and overall

wellbeing. Therefore, the central purpose of this research was to explore the nature of the

experiences of these individuals. One important component of psychosocial

development, particularly during late childhood and adolescence, is the nature of peer

relationships. This resulted in two secondary goals for this study which explored the

nature of peer relationships and social behaviours in the psychosocial development of

children and adolescents diagnosed with early-onset MS. The following chapter provides

a review of the related literature on the following topics. Initially a review of the

literature on MS, specifically on MS in childhood and adolescence is presented. Then,

the roles counsellors can have in the treatment of chronic illnesses is reviewed. Following

this is the theoretical framework for this study. Next, a review of the literature on peer

relationships as a context for psychosocial development is given; followed by a review of

the literature on the connection between psychosocial development, peer relationships,

and chronic illness. Subsequently, there is a review of literature addressing social skills as

a factor in peer relationships. Finally, there is a short review of previous methodology

used for similar research projects.

Multiple Sclerosis: An Overview

Multiple Sclerosis as a Neurological Disease

Multiple sclerosis is an unpredictable, and at times disabling, disease of the

central nervous system. For unknown reasons, the body's immune system begins to

attack the myelin sheath which surrounds and protects the nerves, causing inflammation

and often destroying the myelin in patches (Multiple Sclerosis Society of Canada, 2004). An estimated 50,000 Canadians have multiple sclerosis (Multiple Sclerosis Society of Canada, 2004). Estimated prevalence rates range from one MS case per 500 people to one in 1,000 across the country, depending on the region (Multiple Sclerosis Society of Canada, 2004).

As of yet, there are no known causes of multiple sclerosis. However, researchers have developed several hypotheses about factors which may be involved in MS. For example, there is some evidence that a cold climate with relatively little sunshine is an environmental factor (O'Connor, 2002); MS may be triggered by a common virus (Multiple Sclerosis Society of Canada, 2004); and certain people are more susceptible to developing MS because of genetic factors (Banwell, 2004; Multiple Sclerosis Society of Canada, 2004; O'Connor, 2002).

There are three main types, or progressions, of MS. Relapsing-remitting MS is the most common; approximately 90% of adults with MS present this form (Banwell, 2004). This type is characterized by multiple episodes or attacks, separated by periods of at least one month of partial or complete recovery (Banwell, 2004; O'Connor, 2002). An attack is the appearance of new symptoms, or the significant worsening of old symptoms (O'Connor, 2002). The second type of MS is secondary progressive. Individuals with secondary progressive MS start out with relapsing-remitting MS, but about 80% of them may eventually enter a phase of continual worsening of the disease without remission (O'Connor, 2002). The third type of MS is primary progressive, which affects approximately 15% of individuals with MS (O'Connor, 2002). In this type, the

neurological disability worsens over time without improvement and no clear delineation between attacks from the very onset of the disease (Banwell, 2004; O'Connor, 2002).

Symptoms of MS can vary from individual to individual, and even within the individual. Symptoms often vary because different areas of the nervous system may be attacked (O'Connor, 2002). However, there are many symptoms which are common among individuals with MS. These symptoms may include vision, memory, and bladder difficulties, pain, weakness, numbness, partial paralysis, loss of coordination, fatigue, and depression (Multiple Sclerosis Society of Canada, 2004; O'Connor, 2002). Some individuals may experience only one or two of these symptoms while others may experience the majority of these symptoms. There are no known cures for the disease; however there are many treatments available to manage the symptoms and even modify the progression of the disease.

Treatments for Multiple Sclerosis

There is a significant amount of uncertainty about the future health and wellbeing of multiple sclerosis sufferers, due to the unpredictable and often debilitating nature of the disease (McCabe, McKern, & McDonald, 2004). However, a variety of treatments are available to individuals with MS. These treatments can ease the impact of symptoms and even modify the progression of the disease. It has only been in the last decade that disease-modifying drug treatments have become available. These treatments have been demonstrated to reduce the frequency and severity of MS attacks in individuals with relapsing-remitting MS (O'Conner, 2002). Other medicinal and non-medicinal therapies are also available to manage the day-to-day experience of MS symptoms (e.g., pain, bladder problems, fatigue). Finally, peer groups, counsellors/psychologists, social

workers, and caregivers also provide important care and support for the individual's emotional and psychological needs.

Early-onset Multiple Sclerosis

The occurrence of multiple sclerosis prior to the age of 18 is considered to be quite rare. In fact the actual prevalence of pediatric MS is unknown (Banwell, 2004). However, research has estimated between 1.2% and 5% of individuals with MS experience their first symptoms prior to the age of 16 (Banwell, 2004; Gadoth, 2003; Ghezzi et al., 1997; Ghezzi et al., 2002; Kalb et al., 1999; Ozakbas et al., 2003). Gadoth (2003) calculated the frequency of MS onset prior to age 15 at 1.35-2.5:100,000. Yet another study identified 17% of 418 patients were diagnosed by age 21 (Pinhaus-Hamiel, Barak, Siev-Ner, & Achiron, 1998). However, due to the difficulty of diagnosing MS, many individuals are not officially diagnosed in childhood and adolescence.

The course of early-onset MS in adolescents seems to be similar to adults, with the majority of early-onset MS following a relapsing-remitting course (Banwell, 2004; Boyd & MacMillan, 2000; Gadoth, 2003; Ghezzi, et al., 1997; Ozakabas, Engemen, Idiman, Baklan, & Yulug, 2003; Simone, Carrara, Tortorella, Ceccarelli, & Livrea, 2000). However, a small proportion of children will go on to develop secondary-progressive MS (Banwell, 2004; Boyd & MacMillan, 2000; Gadoth, 2003; Ghezzi, et al., 1997; Ozakabas, et al., 2003; Simone, et al., 2000). Finally, primary progressive MS is quite infrequent for individuals with early-onset MS (Banwell, 2004; Boyd & MacMillan, 2000; Gadoth, 2003; Ghezzi, et al., 1997; Ozakabas, et al., 2003; Simone, et al., 2000), though there have been reports of its occurrence (Gadoth, 2003; Ghezzi, et al., 1997).

Despite the similarities between adult and early-onset MS, the young individuals diagnosed with the disease face some unique challenges.

A Unique Experience

Children and adolescents diagnosed with multiple sclerosis face many of the same hardships as adults diagnosed with MS. That is, they experience the same neurologically-based symptoms which impact the day-to-day functioning of the individual. The most prominent symptoms for pediatric MS have included sensory disturbances, vision problems, motor disturbances, gait abnormalities, and balance problems (Ghezzi et al., 2002; Ozakbas et al., 2003; Simone et al., 2000). Luckily, the majority of youth will recover from their first attack or are left with mild residual disability, though some may be left with significant disability (Gadoth, 2003).

However, children and adolescents diagnosed with MS face some unique challenges. Not only do these individuals have to face the same developmental tasks and challenges as healthy children and adolescents, but they now must add in the extra complication of a chronic illness. Therefore, it is important to address how the symptoms and associated secondary factors of MS impact the development of these children and adolescents.

Early-onset MS can impact how a child develops cognitively. Rao et al. (1991) found cognitive function to be an important factor in determining the quality of life of individuals with MS. Banwell (2003) reports that "slower thinking and difficulties with problem solving, concentration and memory are common in MS, especially in kids" (p. 6). As such, these individuals are at higher risk to experience academic difficulties. This is further supported by a small study done by Kalb et al. (1999). These researchers

examined nine individuals diagnosed with MS before the age 18. Results demonstrated that, in general, cognitive test scores were in the normal range. However, there was significant individual variability within the group. The researchers discussed several cases in which the individual's MS interfered with cognitive functioning, including semantic verbal memory retrieval difficulties, and sensorimotor and visual deficits. These cognitive challenges could potentially be a risk for the children's or adolescents' identity development, self-esteem, and social relationships.

MS can also impact youth on an emotional level. For example, they may feel increased insecurities about their bodies because of the unpredictable nature of the disease, never quite knowing how their bodies will respond from moment to moment. They are also at risk for depression and mood-swings. Banwell (2004) reported that emotional instability had been a significant issue for a number of the early-onset MS patients at the Pediatric MS Clinic at the Hospital for Sick Children in Toronto. Depression had been diagnosed in three patients (Banwell, 2004). Unfortunately, the total number of patients was not reported, therefore it was not possible to determine how this number of individuals with depression differed from the average population. Nonetheless, it is important for clinicians to remember that youth with MS can also suffer from depression and are at risk for emotional instability.

The unpredictable nature of MS, and the risk of disability, can also impact the social development of individuals with early-onset MS. However there is virtually no research addressing this component of development and wellbeing. Children and adolescents with a chronic illness are at higher risk of being isolated by peers (Brown & Macias, 2001; Kliewer, 1997). Specifically for youth with MS, they are more likely to

have to sit out of physical activities with their peers due to the impact of MS on their physical functioning. Trying to get one's peers to understand the complexities of MS can be an added challenge to peer relationships.

The cognitive research (e.g., Kalb et al., 1999; Rao et al., 1991) also has important implications for peer relationships. That is, peers may perceive some individuals with early-onset MS to be of lesser intelligence, resulting in teasing, bullying, and even isolation. However, youth with MS who display these cognitive limitations are not necessarily of lesser intelligence, they may just have trouble accessing the information. Kalb et al. (1999) hypothesized that cognitive impairments could impact the child or adolescent's peer relationships, in addition to other areas of one's life, and this impact could have consequences on self-esteem and self-confidence. The results of their study did not demonstrate the predicted negative impact. However, the researchers used quantitative measures to assess these factors in spite of having a very small sample size. As such, it is not possible to arrive at any definitive conclusions based on their study. The emotional challenges faced by youth with MS can also have a negative impact on their peer relationships. For example, peers may misinterpret mood-swings and depression and subsequently reject the individual with MS. The psychosocial development and overall wellbeing of children and adolescents with early-onset MS is threatened by the disease. Therefore, it is important to identify treatments which address these areas.

Treatment of Early-onset Multiple Sclerosis

Treatments for early-onset multiple sclerosis are just beginning to be uncovered. The disease-modifying treatments used for adults are also being used for children and adolescents with MS (Banwell, 2004; Gadoth, 2003). Research has only just begun to

look at the safety and efficacy of these medications for this age group, though case studies look promising (Banwell, 2004; Gadoth, 2003) Corticosteroids are also used in treatment for acute relapses of the disease (Banwell, 2004; Gadoth, 2003). These drugs shorten the duration of the MS exacerbation. However some of the side effects (e.g., weight gain) associated with steroid use can be very distressing to adolescents, especially girls (Thies, 1999). All of these drugs address the physical symptoms of the disease, but they do not address the social or emotional factors which may be associated with the disease.

Youth with MS are treated either by pediatric neurologists, who may have limited experience with MS, or adult neurologists, who may be unfamiliar with the distinctive needs of this age group (Boyd & MacMillan, 2000). As a result, the individual's overall wellbeing may or may not be adequately addressed by their current healthcare team. However, measures can be taken to ensure that the needs of these individuals are addressed. For example, by "using a multidisciplinary approach, [pediatric professionals] can address health and developmental issues specific to children with MS and their families" (Boyd & MacMillan, 2000). It is only recently that pediatric MS professionals have recognized this need and have made a move to develop a multidisciplinary team in order to address the entire wellbeing of individuals with early-onset MS.

A Role for Counsellors

Wallander and Robinson (1999) suggested that traditional pediatric medicine has not placed sufficient priority on helping children with psychosocial maladjustment. Research has demonstrated that the psychological and social needs of children with chronic illnesses and their families are not met by this traditional system (Bauman,

Drotar, Leventhal, Perrin, & Pless, 1997). According to Farmer, Clark, and Marien

(2003), families are frustrated by the gaps in services that jeopardize their children's

health, development, and everyday functioning. Recently, however, the World Health

Organization has moved towards a more holistic vision of health and disability. This new

perspective of healthcare has shifted its focus to include an individual's social, emotional,

and physical wellbeing (World Health Organization, 2002). Nonetheless, it is still

relatively rare that pediatric psychologists, counsellors, or other professionals interested

in children's development are made integral members of the treatment team for youth

with chronic illnesses (Drotar, 2002; Wallander & Robinson, 1999). The Canadian

healthcare system would do well to consider implementing the holistic vision of the

World Health Organization by attempting to move towards an interdisciplinary approach

to treatment for children and adolescents with chronic illnesses like early-onset MS.

An interdisciplinary approach to healthcare can be valuable on a number of levels.

Drotar (2002) outlined numerous ways in which interdisciplinary collaboration can be

beneficial for all involved. First and foremost, children and families can have access to

the expertise offered by different professionals. This improved access allows children to

receive services that meet their own personal needs. Second, there is opportunity for

mutual enrichment of knowledge and perspectives within the members of the

interdisciplinary team in that they can benefit from each other's expertise. For example,

psychologists and counsellors can benefit from the knowledge and clinical care

experience of physicians, while physicians can also benefit from the research, experience

and professional perspectives or frameworks of psychologists and counsellors. An

interdisciplinary approach may help to address all the needs of an individual in order to promote the individual's overall wellbeing.

Counsellors and/or psychologists can play an integral role within an interdisciplinary team. These professionals can provide valuable services that are not offered by traditional healthcare services. For example, Farmer, Marien, Clark, Sherman, and Selva (2004) suggested that psychologists can provide service by screening children for unmet needs, introducing more effective approaches to chronic care management, and evaluating outcomes. Counsellors and psychologists may also be more sensitive to the developmental events and transitions characteristic of childhood and adolescence. Specifically, they may draw on developmental psychology when considering adjustment and adaptation to chronic illness (Feummeler, 2004). In addition, Leslie, Sarah, and Palfrey (1998), suggested that pediatricians do not, traditionally, have the skills to address other concerns such as sexuality, occupational choices, and independence. Yet these are not unusual concerns for adolescents with chronic illnesses, and ones which counsellors are often trained to help with. Therefore, psychologists and counsellors can promote the physical and mental health of children with chronic illnesses by addressing developmental needs that are not usually attended to by physicians (Fuemmeler, 2004). Psychologists and counsellors can also act as a liaison between school and health professionals (Lightfoot, Wright & Sloper, 1999; Nabors & Lemekuhl, 2004; Power, Shapiro, & DuPaul, 2003). Specifically, they can assist in enhancing academic achievement, emotional adjustment (i.e., upon school reintegration), and facilitating peer relationships (Sexon & Madan-Swain, 1993). Friends can be an important source of emotional support for adolescents with MS; however negative peer relationships can also

be damaging to psychosocial development. Therefore, addressing the social system of peer relationships is an important issue counsellors can assist with in the treatment of children and adolescents with chronic illnesses (La Greca, 1990). Overall, counsellors and psychologists can play an important role in promoting the overall wellbeing of youth with chronic illnesses such as multiple sclerosis.

Youth with chronic illness, specifically MS, could greatly benefit from an interdisciplinary approach that addresses their entire wellbeing. For example, improved communication between the different systems (e.g., school, family, pediatrician, occupational therapist, etc.) involved in a child's or adolescent's life would improve care for the individual. An interdisciplinary team can also address other areas of the individual's life beyond physical health. Some of the issues that could be addressed include reducing the risk for behavioural, social and emotional disorders, effective responses to those problems should they arise, and better coping strategies (Elander and Midence, 1997). In addition, Shiu (2001) argued "early help for children with chronic illness is important if they are to develop and maintain the healthy relationships with their peers that will enable them to better cope with many aspects of their illness" (p. 274). All of these issues could be addressed by services provided by counsellors.

One particular service that may be provided by counsellors is psychosocial interventions. To date, there are no programs specifically designed for youth with MS. However, there have been several psychosocial interventions developed to address the mental health and over-all wellbeing of youth with chronic illnesses. Bauman and colleagues (1997) presented one of the first systematic reviews of the literature on these types of interventions. In their review, they reported that positive effects were found for

several programs, including programs designed to promote knowledge and self-management in asthma, one examining school reintegration of children with cancer, and support and coordination of care among parents of children with a range of conditions. Additional programs that are available address issues such as fostering peer-learning, social skills, illness awareness and management, school issues, self-esteem and self-efficacy, and decision-making. However, most of the programs reviewed did not have evaluation studies published; consequently it is difficult to determine the efficacy of the programs.

In addition to the previously identified roles for counsellors and psychologists, these professionals may contribute to the treatment of youth with chronic illnesses by continuing to develop and evaluate psychosocial interventions. First, though, counsellors need to develop a systematic approach for identifying and working with children with chronic illness (Thies, 1999). Specifically, for youth with MS, it is important to identify which issues may need to be addressed through psychosocial interventions. One of the issues that may play a significant role in psychosocial development of individuals with early-onset MS is peer relationships. However, very little is known about the psychosocial development of youth with MS, or the role peer relationships may have on that development. Therefore, the purpose of this study was to explore the impact peer relationships may have on the psychosocial development of youth with this disease. In the following sections the role of peer relationships on psychosocial development is explored further; included is a discussion of chronic illness as a factor influencing those peer relationships. First, however, two important theories which guided the development of this research are presented.

Theoretical Framework

Two separate, yet complimentary, theories were utilized to provide a framework

for this study. These two theories included Bronfenbrenner's (1977) ecological theory

and Erikson's (1968) theory of psychosocial development. The theories help to create an

argument for the importance of peer relationships in the psychosocial development of

children and adolescents.

Bronfenbrenner's Ecological Theory

Bronfenbrenner's (1977) ecological theory takes into consideration human

development within a larger social context. According to Bronfenbrenner (1977), the

social context can be examined in terms of systems: the microsystem, the mesosystem,

the exosystem, and the macrosystem. Each system describes different, intertwined

arrangements of relationships between individuals and their environments. Of particular

relevance to the present study is the microsystem, "the complex of relations between the

developing person and environment in an immediate setting containing that person"

(Bronfenbrenner, 1977, p. 514). Bronfenbrenner suggested that psychological research

has generally disregarded the role of those other than the experimenter and subject in

social interactions. Therefore, he proposed that an ecological experiment should take into

account reciprocal processes of all involved.

Bronfenbrenner's concept of the microsystem provides a basis for examining the

psychosocial development of children and adolescents with a chronic illness, particularly

early-onset MS. Specifically, researchers should not only look at how individual children

experience early-onset MS, but should also study how the broader social environment

(e.g., other children in the peer group) impacts the individual's psychosocial

development. Failing to do so would result in the neglect of the total social system that is actually functioning in the situation.

Erikson's Theory of Psychosocial Development

Beyond the ecological perspective, several theorists have stressed the importance of the period of childhood and adolescence for positive identity development and autonomy. For the purpose of this study, a focus will be placed on Erikson's (1968) theory of psychosocial development. In childhood, individuals develop numerous skills and competencies in school, at home, and in peer relationships. According to Erikson (1968), developing this sense of industry is essential to healthy psychosocial development. Children learn how to be productive, which leads to a sense of competency (Kliewer, 1997). Building a sense of competency is important in developing self-esteem. Also important at this stage is a connection with peers and learning how to communicate with them. Children gather information about the rules and obligations of friendship relationships. They learn the nature of a give-and-take relationship and the nature of a mutual relationship. Comparison with peers becomes increasingly important, and a negative evaluation of one's self compared to others is especially damaging at this time (Craig, Kermis, & Digdon, 1995). However, Erikson (Erikson, 1985) argued that the danger at this stage "lies in a sense of inadequacy and inferiority" (p. 260). If a child feels he or she is unable to develop the skills and tools typical of this age, he or she may have difficulty identifying with his or her peers (Erikson, 1985). Accordingly, children with MS who may not be able to develop the same skills as peers, due to physical or cognitive limitations, may suffer from inadequate connection with peers. Further, Erikson (1985) suggested that children are beginning to recognize differences between individuals

and begin to feel these differences will decide one's worth. As a result children begin to judge each other based on similarities and differences.

In adolescence, many individuals go through a stage of identity crisis (Erikson, 1968). Erikson (1968) posited that this crisis is "a necessary turning point, a crucial moment, when development must move one way or another, marshalling resources of growth, recovery, and further differentiation" (p. 16). At this stage, the adolescent must find the answer to "Who am I?" that is in agreement to one's self and others around them (Cloninger, 2000). They need space to freely explore various roles without the obligation experienced in adulthood. Adolescents need to sort out their various roles and seek basic values and attitudes (Craig, et al., 1995). It is also important to recognize that peer relationships greatly influence the development of a sense of identity. The adolescent's world really starts to expand beyond that of the family to that of peers. The peer group becomes increasingly important as more rules and norms are developed within this interaction (Rubin, Bukowski, & Parker, 1998). Peer pressure and conformity are important issues that the adolescent may face. According to Erikson (1985), adolescents can become "remarkably clannish, and cruel in their exclusion of all those who are 'different'" (p. 262). Therefore, the relationships one does or does not develop during this time can greatly impact how an adolescent forms his or her own identity. Adolescents are eager to be affirmed by their peers (Erikson, 1985). The task of identity formation is also connected to that of autonomy development (Cloninger, 2000). Adolescents need to learn to assert themselves and expand outside of the family environment to that of peers and other groups. As they do this, adolescents develop a sense of independence and self-sufficiency. However, adolescence can be a stressful time; therefore, those who can find

support from some relationships (e.g., friends) are better equipped to deal with the stressors in their lives.

Some may question the relevance of these theories to the present study because they were developed over three decades ago. However, the current research on children and adolescents with chronic illnesses repeatedly addressed the exact issues that these theorists proposed. For example, many studies addressed the importance of examining peer relationships in the psychosocial development of young individuals with chronic illness (e.g., Alderfer, Wiebe, & Hartmann, 2001; Boekaerts & Röder, 1999; Kliewer, 1997). In addition, many more studies stressed the importance of addressing how developmental tasks are impacted by chronic illness. The developmental tasks identified by researchers coincide with Erikson's theory in that they address concepts like competency, identity, positive peer relationships, independence and autonomy (e.g., Creswell, Christie, & Boylan, 2001; Kliewer, 1997; Madsen, Roisman, & Collins, 2002). Therefore, it seemed quite justifiable and relevant to use Bronfenbrenner (1977) and Erikson (1968) as theoretical perspectives for the current study.

Chronic Illness and Psychosocial Development

The psychosocial development of children and adolescents with chronic illnesses has been operationalized in a variety of ways by researchers. For example, psychosocial development has been operationalized as self-esteem, social isolation behaviour problems, and school achievement (Boekaerts & Röder, 1999), diagnoses from the Diagnostic and Statistical Manual of Mental Disorders-Third Edition (Cadman, Boyle, Szatmari, & Offord, 1987), behavioural and emotional problems, social adjustment, peer relationships and academic performance (Brown & Macias, 2001), anxiety, depression,

aggression, acting out, social withdrawal, or peer difficulties (Wallander & Robinson, 1999). Also, the concept of psychosocial development has been studied across a variety of chronic illnesses which are manifested in different ways (e.g., Adams, Streisand, Zawacki & Joseph, 2002; Boekaerts & Röder, 1999; Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000). As a result of psychosocial development being studied in different ways and with a variety of different chronic illnesses, there are mixed results as to whether or not a child or adolescent with a chronic illness may experience adjustment difficulties.

Boekaerts and Röder (1999) presented a review of the literature on the psychosocial adjustment of youth with chronic illnesses. Across all chronic illnesses that have been studied, they concluded that higher school absence rates did not always mean that these individuals were at risk for decreased school performance. Also, it was reported that across all studies reviewed, children with chronic disease had increased behaviour problems in comparison to their healthy peers. This phenomenon was attributed to increased internalization of problems such as depression, social withdrawal, and anxiety. Finally, the authors reported that there are few universal effects of chronic illness on social functioning; however some youth with certain diseases reported difficulties in peer relationships. The authors argued that there is a need to look at specific illnesses and individual variation within illnesses. For example, in their review, they found that children with certain chronic illnesses (e.g., spina bifida, epilepsy) were more prone to academic difficulties. The illnesses given as examples impact the neurological system. In addition, children with sensory and neurological disorders had the highest risk of having psychological problems. La Greca, Bearman, and Moore

(2002) reported that children with central nervous system-related illnesses had trouble developing age-appropriate peer relations. Due to the nature of multiple sclerosis, this supports the need to specifically address the psychosocial development of youth with this disease.

<div align="center">Peer Group as Context for Psychosocial Development</div>

As the peer group is becoming increasingly important during late childhood and adolescence, it provides an important context for psychosocial development. In the theoretical framework, it has been demonstrated that childhood and adolescence is a critical time in the development of self, and the peer group is one context in which this occurs. According to Harry Stack Sullivan (1953, as cited in Rubin et al., 1998), the specific function of peer group relationships is for the development of self and sense of wellbeing. The peer group is generally conceptualized by theorists as an important developmental context that moulds and sustains the behaviours of its members (Rubin, et al., 1998). Specifically, research has supported the psychological importance of social experiences within the peer network (e.g., Sullivan, 1953 as cited in Rubin, et al., 1998; Berndt, 1996; Hartup, 1996). Social relationships influence children's and adolescents' "sense of self, social closeness to others, self-esteem, and their perceptions of their ability to perform and cope effectively" (Shiu, 2001, p. 274). The quality of an individual's peer relationships is related to one's overall sense of wellbeing.

<div align="center">*Positive Peer Relationships*</div>

According to Bukowski, Newcomb, and Hartup (1996), friendships promote development and adaptation. Positive experiences in peer relationships (e.g., supportive friendships) provide important opportunities for development in a variety of domains,

including psychosocially. Specifically, positive peer relationships provide a context for the development of prosocial skills (e.g., Berndt, 1982), emotional development (e.g., Dunn, 2000), and social development (e.g., Hartup 1996). Studies have shown that children who have friends are more socially competent than children without friends (Bukowski, et al., 1996). Positive peer relationships can also provide support, reassurance of one's worth, and foster identity testing (Brown, 1989). If the child has at least one friend who has qualities for serving a protective function (e.g., socially skilled, well liked, externalizing behaviours), the risk of victimization for the target child decreases (Hodges, Malone, & Perry, 1997, Schwartz, Dodge, Pettit, Bates, & The Conduct Problems Prevention Research Group, 2000). It is also reported that friendships encourage problem-solving behaviours through cooperation and better understanding of the other's needs and abilities (Newcomb & Bagwell, 1995). Positive peer relationships can be a particularly important source of social support for individuals with chronic illnesses. La Greca and colleagues (2002) suggested that support from close friends may help buffer stress reactions and facilitate adaptation to the illness. For children and adolescents with chronic illness, it is possible that positive peer relationships protect the individual from the psychosocial risks of the disease. Specifically with MS, positive peer relationships may provide the support and stability needed to cope with an otherwise unpredictable disease.

Negative Peer Relationships

Negative peer relationships can be stressful for children due to both the experience itself, and the subsequent lack of social support (Shiu, 2001). Sullivan (1953, as cited in Rubin et al., 1998) suggested that being isolated from the peer group during

childhood and adolescence would lead the individual to have concerns about his or her

own capabilities and acceptability as a desired peer. Those who would be unable to

establish meaningful and reciprocal relationships within the peer group would develop a

feeling of inferiority which could contribute to poor psychological wellbeing (e.g.,

loneliness) (Sullivan, 1953, as cited in Rubin et al., 1998). Without positive social

experiences, individuals are more likely to experience feelings of loneliness, depression,

and a reduced sense of self-worth. Children and adolescents with chronic illness can be

more vulnerable to these negative peer experiences due to the social stigma attached to

disease and disability (Kef, et al., 2000; La Greca, 1990). Additionally, individuals with

chronic illnesses such as MS may face other barriers to healthy peer relationships,

including feeling that they have nothing to offer peers, fears that peers may have of the

illness, or lack of peer understanding of the illness.

<div align="center">Peer Relationships as a Factor in Chronic Illness</div>

Previous research has presented mixed findings in regards to the peer

relationships of children and adolescents with chronic illnesses (e.g., Alderfer, Wiebe, &

Hartmann, 2001; Brown & Macias, 2001; Palmer, et al., 2000; Pendley, Kasmen, Miller,

· Donze, Swenson, & Reeves, 2002). For example, Pendley et al. (2002) found that

adolescents with diabetes perceived their peers to be helpful and supportive. However,

Palmer et al. (2000) found that adolescents with cancer commonly reported feeling

isolated and alone. Further, Brown and Macias (2001) presented mixed findings in their

review article. Some articles they reviewed concluded that youth with chronic illness

were at increased risk for difficulties in peer relationships, while other articles reported

that these youth did not differ from their healthy counterparts. However, it is important to

keep in mind some of the explanations for the discrepancies in the studies, including: 1) difficulties in identifying adjustment in youth; 2) the use of different sources of measurement for adjustment; 3) the use of small samples in studies reporting no differences between youth with chronic illnesses and their healthy peers; and 4) the difficulty of comparing studies which examined a variety of chronic illnesses (Wallander & Robinson, 1999). The following is a review of some of the important variables which can impact peer relationships for individuals with chronic illnesses like MS.

"Close" Friends and the Larger Peer Group

One variable that impacts the perceived quality of peer relationships is who one refers to when asked about peer relationships. It is quite common for peer relationships to be operationalized as close friends or best friends (e.g., Kef, et al., 2000; Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003). This type of relationship is characterized as being reciprocal in nature, especially in terms of affection, and is completely voluntary (Rubin, et al., 1998). However the larger peer group can also have an impact on psychosocial development (Rubin, et al., 1998). The larger peer group is a collection of individuals who have some degree of reciprocal influence over each other (Rubin, et al., 1998). Groups may form spontaneously through common interests, or formally, like in a classroom (Rubin, et al., 1998). As a result of the different characteristics of close friends and peer groups, these relationships also may have different effects on an individual's psychosocial development.

A recent study examined the social networks of visually impaired and blind adolescents (Kef, et al., 2000). They found that these individuals generally had smaller peer networks than healthy adolescents. The majority of participants reported having less

than five friends, having none or one support person in the school or work category, and having none or one support person in the club-mates category. Nonetheless, they identified that there was also satisfaction with the amount of support received from peers. The problem with this study, however, is that close friends were combined with classmates to make up the category of 'peers.' This may result in inaccurate results because it is not possible to differentiate between the influence of close friends and the larger peer group on the support measure. Many other studies which address peer support also examine the close, intimate relationships which are sources of support for children and adolescents with chronic illness (e.g., Pendley, et al., 2002; Reiter-Purtill, et al., 2003). However, for children and adolescents, the larger peer network (e.g., classmates) is also likely to have an impact on their psychosocial development. There is an absence of research addressing the larger peer network and whether or not the interactions within these relationships are positive or negative.

One study identified differences between the larger peer group and close friends (Lightfoot, et al., 1999; Mukherjee, Lightfoot & Sloper, 2000). The researchers studied the perceptions of children and adolescents with chronic illnesses in regards to the impact of their illness on their school experience. Participants were interviewed in their homes, and also created a diagram of themselves and sources of support at school. One of the themes which arose was in regards to their peer relationships. Some students found that their peer relationships were not impacted by their chronic illness. Others, however, struggled with being ignored by their peers and being the focus of curiosity. Over a third of the participants mentioned being bullied, mostly because they were seen to be different from their peers. It is generally reported that 15% of students are bullied (e.g., Rigby,

1999). Therefore, the research by Lightfoot et al. (1999) and Mukherjee, Lightfoot and

Sloper (2000) would suggest that individuals with chronic illnesses are at greater risk for

peer victimization. The researchers also reported that, in response to the bullying,

students would isolate themselves, retaliate, or avoid doing things which would lead to

bullying. The latter often resulted in the students jeopardizing their medical needs or

avoiding school altogether. It was not reported how these anti-social behaviours further

contributed towards social isolation. Nonetheless, these students with chronic illnesses

also developed close friendships in school. Friends helped deal with curiosity of other

students by explaining the illness, and with bullying by standing up for the individual

with the chronic illness. Friends also helped by providing physical care (e.g., carrying

bags and pushing wheelchairs), helping with school work that was missed, and keeping in

touch with classmates during absences.

Degree of Disability

The degree of disability experienced by individuals with a chronic illness may

impact their ability to develop or maintain positive peer relationships. Based on adult MS

research, withdrawal from social activities and a shrinking of friendship networks was

common among individuals with MS, especially those with severe disability (Hakim et

al., 2000). However 81% of those who had mild disability continued to visit friends and

engage in social activities outside of the home (Hakim et al., 2000). Nine out of 10

patients with mild MS kept in touch with previous friends and colleagues, but only 47%

of severely disabled subjects received visits from old friends in the month preceding the

interview (Hakim et al., 2000). This research suggests that the degree of disability

experienced by individuals with MS can impact their peer relationships.

To date there is no research available studying the impact of disability on peer

relationships for youth with MS. However, research that addressed other childhood

chronic illnesses has also suggested that the degree of disability can have a negative

impact on these relationships. Thies (1999) argued that the prolonged symptoms of

chronic illness decrease energy, making it difficult for youth to participate fully in the

social and academic life of the school. Children with physical restrictions are less

involved in social activities than children without physical restrictions (Meijer, et al.,

2000). However, the researchers did not identify the severity of restrictions even though

they used a 5-point scale ranging from no restrictions to severe restrictions. The physical

restrictions were also limited to locomotion and did not assess restrictions that may

interfere with such things as eating, writing, or throwing a ball. In addition, children with

pain were described as less involved in social activities and reported more social anxiety

than children who do not experience pain with their illness (Meijer, et al., 2000). Other

researchers (Cadman et al., 1987) have found that individuals with disability reported less

competence in recreational activities than those without disability. The more severe and

prolonged the symptoms of a chronic illness are, the more likely the illness is to threaten

the individual's overall wellbeing and psychosocial development.

In addition, youth with chronic illnesses face developmental issues which may be

exacerbated by increased disability, subsequently impacting peer relationships. One

developmental issue that is prevalent in childhood and adolescence is body image.

According to Sexon and Madan-Swain (1993), "any major physical change threatens the

student's body image and, ultimately, self-esteem, potentially causing discomfort in peer

interactions" (p. 118). Henning and Fritz (1983, as cited in Sexon & Madan-Swain, 1993)

suggested that students' fears and worries about their physical appearance and disease were the most common causes for referral for mental health interventions (e.g., counselling) to facilitate school re-entry. Specifically, some adolescents have reported that they fear peer ridicule and teasing because of changes in their physical appearance (Sexon & Madan-Swain, 1993).

Peers' perceptions of an individual with a chronic illness are also impacted by the degree of disability. "Adolescent peers are more likely to avoid interaction with the student with a chronic illness due to fears of associating with someone who is different" (Sexon & Madan-Swain, 1993, p. 118). This risk is likely to increase with more severe, observable disability. Cadman, Boyle, Szatmari, and Offord (1987) found that isolation was much more prevalent among children with chronic illness and disability than children with chronic illness but no disability. Similar to the critique of a previous study, the researchers did not identify the degree of disability, in fact nor did they measure it. This could potentially impact whether or not the child is isolated by peers. Finally, the authors reported that those children who have long-term disability associated with a chronic illness are at risk for problems of social and school adjustment. As a result, peers may perceive these individuals as less intelligent and anti-social.

This research has potential implications for youth with MS and their relationships with their peers. A diagnosis of MS carries with it a risk of physical and cognitive disability. Therefore, individuals with increased disability, because of the MS, may face even more risk with their peer relationships than those who do not experience disability. They may face greater challenges with participating in social activities, be at increased risk for negative body image, and face a greater threat of isolation from their peers. As

such, it is important to understand how degree of disability impacts youth with early-onset MS.

Cultural Milieu and School Interruptions

Children and adolescents spend the majority of their day in the school environment. According to Davis (1989), "the school milieu for growing and developing children or adolescents provides students with opportunities to learn, socialize with peers, experience success, and develop increased independence and control over their environment" (p. 117). However, chronically ill children are more likely to experience absences from school as a result of issues related to their illness. Specifically for youth with MS, they may be unable to attend school due to the severity of their symptoms or they may miss school for healthcare appointments. Frequent and/or extended absences from school disrupt friendship formations and can interrupt friendships (Shiu, 2001). Also, as a result of school absences, almost 40% of youth with chronic illness experience school-related problems, including psychologically and socially (Bloch 1986, as cited in Sexon & Madan-Swain, 1993, Shiu, 2001).

Sexon and Madan-Swain (1993) presented a review of the literature on the importance of the school environment for children's and adolescents' psychosocial development. Specifically, Sexon and Madan-Swain addressed the challenges individuals with chronic illnesses face as a result of being absent from school and during the process of reintegration. Much of a student's social and emotional development is fostered within the school setting (Weitzman, 1984 as cited in Sexon & Madan-Swain, 1993). Therefore, children and adolescents who are physically unable to attend school may feel devalued, experience a decrease in self-esteem, and become even more fearful of being alone and

isolated from peers (Davis, 1989, as cited in Sexon & Madan-Swain, 1993). Sexon and

Madan-Swain (1993) reported that school re-entry for a child or adolescent with a

chronic illness may be as important to his or her social survival as medical treatment is

for the child's physical survival. Prolonged absences decrease the opportunity for contact

with peers and subsequently may impede social interaction (Sexon & Madan-Swain,

1993). It was also reported that students' fear of peer rejection, frequently makes school

re-entry frightening (Chekryn, Deegan, & Reic, 1986, as cited in Sexon & Madan-Swain,

1993).

In the interviews conducted in the study by Lightfoot, Wright, and Sloper (1999),

several themes arose. Some of these themes included school absence, exclusion from

school life and relationships with peers. It was identified that long periods of absence

from school resulted in some students feeling isolated from their peers. However, those

who were able to stay in contact with their classmates while out of school were less likely

to experience this sense of isolation. It was also identified that most of the youth with

chronic illnesses felt excluded to some extent from the school experience while being at

school. This included both curriculum activities and social activities. For example,

students would often miss school trips because of illness or transportation difficulties.

After-school activities were also a challenge for these students as they struggled with

issues of fatigue, physical limitations, feeling self-conscious, and access or transportation

problems. Missing school or not being able to participate in school activities can impede

with an individual's ability to be a part of the school's cultural milieu and to develop

relationships with peers.

Peer Relationships and Early-onset Multiple Sclerosis

To date, virtually no research has been found by the researcher that addresses the peer relationships of children and adolescents with early-onset multiple sclerosis. Nonetheless, one study reported that youth with MS indicated that they have friends, felt popular, and were liked by their peers (Kalb, et al., 1999). However this study had several important flaws: 1) the Self-Perception Profile used was actually developed for healthy individuals not for individuals with chronic illnesses, therefore it may not adequately measure the peer experiences; 2) the use of survey methodology limited the researcher's ability to really understand the unique experiences of the youth interviewed, and the issues which they perceived to be of importance in their peer relationships, 3) the measures did not look at the larger peer group, just close friends; and 4) the individuals surveyed were reported to lack a realistic picture of MS or its potential impact on physical and cognitive functioning.

As negative peer experiences can have an adverse impact on child and adolescent psychosocial development and overall wellbeing, it is crucial to understand peer experiences within the context of early-onset MS. Therefore, one of the goals of this study was to examine the occurrence of perceived positive and negative peer group experiences among children and adolescents with early-onset MS and obtain descriptive data about these experiences.

Social Skills as a Variable in Peer Relationships

The social behaviours of children and adolescents also impact their experiences with peers. To be socially competent, a child or adolescent must be able to: 1) engage in a peer group structure and participate in group activities, 2) be involved in mutually

satisfying and reciprocal relationships, and 3) satisfy individual needs and goals while developing accurate and productive means of understanding peer experiences (Rubin, et al., 1998). As such, children who are socially competent must behave in a certain manner. Specifically, positive social behaviours increase peer acceptance, whereas negative social skills decrease peer acceptance (Coie, Dodge, & Kupersmidt, 1990).

Impact of Chronic Illness on Social Skills

Previous research has reported that children with chronic illnesses are less likely to participate in peer social activities (e.g., Cadman, et al., 1987; Kliewer, 1997). This lack of social participation may be a result of physical disability or number of medical appointments. Children and adolescents may have low confidence in their abilities to participate in recreational activities (Cadman, et al., 1987), and therefore withdraw from these types of social opportunities. Children and adolescents with chronic illnesses are also more likely to experience anxiety and depression than their peers (Thies, 1999), which may be expressed through withdrawn or isolated behaviours.

In addition, Meijer and colleagues (2000) found that chronically ill children are more likely to respond to peers in a socially desirable manner than their healthy counterparts. These children may be trying to keep up socially appropriate appearances, or trying to cope with social expectations. This behavioural response may have a negative impact on children and adolescents with a chronic illness. For example, Thomas, Peterson, and Goldstein (1997, as cited in Pendley et al., 2002) addressed peer support in adolescents with diabetes and found that adolescents were less likely to adhere to their treatment and more likely to choose actions consistent with peer desires.

Some research has also suggested that children and adolescents with a chronic illness tend to display negative social behaviours (Phipps & Steele, 2002). For example, many adolescents in a support program for cancer victims reported that they withdrew from peers because they did not feel their struggles were understood (Palmer, et al., 2000). In addition, Meijer and colleagues (2000) reported that chronically ill children were perceived by their parents to display more submissive social behaviours compared with healthy children. The adolescents in this study confirmed these parental observations in their self-reports. These negative social behaviours can interact with the stigma of a chronic illness to further impact the social experiences of individuals with the illness. Therefore, it is important to study the social behaviours of children and adolescents with early-onset MS as contributors to perceived peer acceptance.

Previous Methodology

Much of the previous research on youth with chronic illness has relied on survey methodology to gain an understanding of their experiences. However, this type of method does not often provide an adequate, detailed description of an individual's experiences in social and psychosocial processes (e.g., peer relationships). For example, the Self-Perception Profile has been used by some researchers (e.g., Kalb et al., 1999; Meijer et al., 2000). However, this measure was designed for healthy children and adolescents; therefore it may not tap into the unique experiences of an individual with a chronic illness. Other studies have used quality of life measures (e.g., Madsen, Roisman, & Collins, 2002). However, quality of life measures tend to have an insufficient number of items devoted to assessing social functioning (Adams, et al., 2002) and therefore these survey methods may be less adequate and less reliable indicators of social functioning.

Another commonly used scale is the Child Behavior Checklist (see review of literature in Boekaerts & Röder, 1999). However, once again this measure is not designed to tap into the unique experiences of youth with a chronic illness, or to provide an opportunity for them to give more explicit details about the circumstances around their experiences.

It has been argued that children's and adolescents' perceptions of their illness and its consequences play a salient role in predicting adjustment (Boekaerts & Röder, 1999). Therefore, it is necessary to employ a research methodology which can tap into these perceptions, especially of the issues that they deem to be most relevant to them. Despite the research presented, the experiences of children and adolescents with MS are mostly unknown. When researchers are unable to find previous research on an area like this, they may choose to gain a greater understanding of that area. In order to do this, it is important to engage with the individuals who live in or experience the area under study, understand their experiences, and try to build a framework that would explain the range of experiences they have had. For this reason, the present study utilized grounded theory, which aims to explain social and social psychological processes.

Conclusion

The focus of this study was to address the nature of peer relationships and social behaviours in the psychosocial experiences of children and adolescents diagnosed with early-onset multiple sclerosis (prior to age 18). Previous research has suggested that youth with chronic illnesses, such as MS, are at risk for negative peer relationships. Peer relationships seem to be important for the healthy psychosocial development of these individuals. Therefore, the possibility of negative peer relationships may place youth with MS at risk for negative psychosocial development. The primary research question for this

study was: What are the experiences of children and adolescents with early-onset MS? The specific sub-goals of the study were to address the following questions: 1) How does a diagnosis of early-onet MS affect the peer social experiences of children and adolescents (both present and retrospectively)? 2) How do the social behaviours of children and adolescents with early-onset MS impact their peer relationships? These questions were explored in detail through qualitative methodology, specifically grounded theory.

CHAPTER 3: METHODOLOGY

The purpose of this chapter is to describe the research methods used in this thesis. The methods were chosen based on best fit for answering the research questions: 1) What are the experiences of children and adolescents with early-onset MS? 2) How does a diagnosis of early-onset MS affect the peer social experiences of children and adolescents (both present and retrospectively)? 3) How do the social behaviours of children and adolescents with early-onset MS impact their peer relationships? Specifically, interviews were used in combination with grounded theory analysis in order to understand the range of psychosocial experiences of youth with early-onset MS. A description of the methods, population, measures, and procedures that were used in collecting and analyzing the data is provided.

Qualitative Methodology

For the purpose of this study, a qualitative design was used. Qualitative research is any type of research that produces findings, or concepts and hypotheses as in grounded theory, that are not arrived at by statistical methods (Glaser, 1992; Strauss & Corbin, 1990). Qualitative research, in general, has no single methodology, but emphasizes the socially constructed nature of reality (Denzin & Lincoln, 1998). The focus of qualitative research is on individuals' lives, stories, behaviour, or group and organizational functioning, or interpersonal relationships (Denzin & Lincoln, 1998; Strauss & Corbin, 1990). Qualitative analysis aims to: 1) uncover the nature of individuals' experiences with a phenomenon, like illness; 2) uncover and understand a phenomenon about which little is known; and 3) provide opportunity to gain intricate details about a phenomenon that is difficult to obtain through quantitative methods (Strauss & Corbin, 1990).

Therefore, the intention of using this design was to most effectively address the interpersonal experiences of the participants, as related to each of the research questions.

Specifically, qualitative methods of analysis will be used on qualitative data. Qualitative data takes the form of descriptive words, unlike quantitative data which is in the form of numbers and measurements. Collection of qualitative data can occur through a variety of techniques, such as interviews, observations, documents, or books (Strauss & Corbin, 1990). For the purpose of this study, qualitative data were gathered through interviews. Qualitative analysis was chosen for this study as the research questions lend themselves more to this type of analysis, as explained above. Also, as this area has rarely been studied before, interviews were chosen as the method of data collection in order to obtain the perceptions of the youth under inquiry. Qualitative data can subsequently be analyzed with quantitative or qualitative methods of analysis. This study analyzed the data through qualitative analysis, which is a nonmathematical procedure. The goal of qualitative analysis is to manage and make sense of the data collected in a verbally descriptive manner. The process is inherently creative and interpretive (Denzin & Lincoln, 1998). The specific strategies of analysis in this study will be discussed later on in this chapter.

Methodology Rationale

Description of Grounded Theory

The research method employed in this study was derived from grounded theory, and is one of many forms of qualitative research methods. Grounded theory was developed by two sociologists, William Glaser and Anselm Strauss (Glaser & Strauss, 1967). According to Charmaz (2002), grounded theorists aim to explain social and social

psychological processes. Grounded theory researchers aim to explain "patterns of action and interaction between and among various types of social units" (Strauss & Corbin, 1998, p. 169).

Grounded theory provides the opportunity to develop theory where there is not any (Glaser & Strauss, 1967). According to Glaser and Strauss (1967), theory is important for several reasons, including being able to predict and explain behaviour, to guide and provide a style for research, and to be usable in practical applications. Strauss and Corbin (1998) suggest that "grounded theory is a general methodology for developing theory that is grounded in data systematically gathered and analyzed" (p. 158). Developing grounded theory is important as it is intended to represent reality, having been generated from diverse data (Strauss & Corbin, 1990). Therefore, it should fit the phenomenon being studied. Also, because it represents reality, the theory should be understood by both the individuals studied and those practicing in the area (Strauss & Corbin, 1990). Finally, the theory should provide direction and control for how phenomenon is addressed by practical applications. Therefore, the purpose of grounded theory is to build theory that is true to and clarifies the area being studied, and provide direction for future research and application.

Grounded theory "uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon" (Strauss & Corbin, 1990, p. 24). This set of procedures includes: three levels of coding procedures, theoretical sensitivity, constant comparative analysis, theoretical sampling, memos and diagrams. With the use of these procedures, concepts and the relationships between them are identified and tested by subsequent data. Concepts are similar data grouped together and given a conceptual label

(Strauss & Corbin, 1990). Also, built into the interrelated data collection and theoretical development is the mandate to strive toward verification of the developing theoretical hypotheses (Denzin & Lincoln, 1998). The resultant research findings make up a theoretical formulation of the reality being investigated.

Appropriateness of Grounded Theory

Grounded theory was an appropriate approach for this study for several reasons. First and foremost, the research questions are social in nature, which fits the goal of grounded theory to explain social processes. Second, the content area of this thesis has rarely been explored. Therefore, there seemed a need to gain a deeper understanding of the unique experiences of youth with MS. Grounded theory lends itself well to doing this by allowing the researcher to not only develop a descriptive account of these experiences, but to begin developing theoretical hypotheses about the social processes taking place. Third, the theory developed out of the present research has the potential for the following benefits: 1) increasing understanding of the experiences of individuals with early-onset MS, 2) guiding future research in this area, 3) and guiding the development of counselling programs, interventions, and services for children and adolescents with early-onset MS.

Philosophical Background

The philosophical underpinnings of grounded theory are derived from the symbolic interactionist perspective of social psychology and sociology. Annells (1996) states that "symbolic interactionism is both a theory about human behavior and an approach to inquiring about human conduct and group behavior" (p. 380). Central to this perspective is the idea of a socially created reality. That is, humans see the world through

perspectives which are developed in interaction with others (Charon, 1979).

Subsequently, humans act towards things on the basis of the meanings that the things

have for them (Blumer, 1969). Also, it is important to note that a process of interpretation

is used to direct and modify the meanings as the situation is dealt with by a person

(Annells, 1996; Blumer, 1969). Therefore, "when human beings associate with each

other, they are involved in interpretive interaction" (Annells, 1996, p. 381).

Central to symbolic interactionism perspective is the concept of the symbol.

Symbols may be words, actions, or objects. Symbols are a class of social objects used to

represent or stand for whatever it is that people agree upon (Charon, 1979). As such,

symbols are conventional: they mean something only because people have agreed upon

the meaning through interaction (Charon, 1979).

Based on these premises, symbolic interactionists approach research from a

qualitative methodological standpoint. First, Blumer (1969) suggests that researchers

need to explore the empirical world:

> The empirical social world consists of ongoing group life and one has to get close
>
> to this life to know what is going on in it. If one is going to respect the social
>
> world, one's problems, guiding conceptions, data, schemes of relationship, and
>
> ideas of interpretation have to be faithful to that empirical world. (p. 38)

Therefore, to understand the empirical world, the researcher must come to understand

people's symbols as they understand them. This exploration can be done through any

"ethically allowable procedure" (p. 41), including observation, interviews, letters and

diaries, public records, and group discussions (Blumer, 1969). Blumer (1969) also

suggests that the researcher must continually be "testing and revising his images, beliefs,

and conceptions of the area of life he is studying" (p. 41). However, he argues that constructing descriptive accounts of what takes place is not sufficient when examining the empirical world. Researchers must also engage in theoretical analysis, as this is "the proper aim of empirical science" (Blumer, 1969, p.43). To test the validity of the developing theoretical propositions, the researcher must return to examining the actual human experiences. Grounded theory provides a methodological approach which fulfills these goals.

Method and Techniques in Grounded Theory

Interviewing

The benefit of using interviews is that it creates the opportunity for the participants to tell their stories. As such, they are able to identify the issues that are pertinent to their own experiences of the subject being addressed. The interview experience may also provide participants with an opportunity for insight into their experiences (Charmaz, 2002). Then, using constant comparison analysis, the researcher continually reviews the data from the interviews looking for common themes. The researcher develops conceptual categories from the data, and that data is used to illustrate the concept (Glaser & Strauss, 1967). Subsequent interviews are guided and focused based on the themes which arose in previous interviews (Charmaz, 2002); however they may also reveal new themes which the researcher can go back and look for in previous interview data. This process is often referred to as theoretical sampling: "sampling on the basis of concepts that have proven theoretical relevance to the evolving theory" (Strauss & Corbin, 1990, p. 176). Grounded theory "is derived from data and then illustrated by characteristic examples of data" (Glaser & Strauss, 1967, p. 5).

Theoretical Sensitivity

Theoretical sensitivity is an important term used in grounded theory. According to

Strauss and Corbin (1990), it is the "attribute of having insight, the ability to give

meaning to data, the capacity to understand, and capability to separate the pertinent from

that which isn't" (p. 42). Therefore, this concept is fundamental to developing theory that

is accurately based on the reality of what is being studied. Theoretical sensitivity comes

from two main avenues. The first is the researcher's exposure to the subject under

question. This exposure can come from familiarity with the relevant literature,

professional experience, or personal experience (Strauss & Corbin, 1990). The second

avenue is through continual interaction with the data (Strauss & Corbin, 1990). This

interaction occurs during the analytic process: as one collects the data, asks questions

about the data, makes comparisons and hypotheses, and develops mini theoretical

frameworks (Strauss & Corbin, 1990). Theoretical sensitivity arises as the researcher

develops insight and understanding about the phenomenon as one interacts with the data.

Constant Comparison Analysis

Constant comparison analysis is a process by which joint coding and analysis

occurs to generate theory (Glaser & Strauss, 1967). This process allows a theory to

develop that is "integrated, consistent, plausible, close to the data" (Glaser & Strauss,

1967, p. 103). Glaser and Strauss (1967) identified four stages to constant comparison

analysis. First, the researcher compares incidents applicable to each category. The

researcher codes each incident in the data into as many categories as possible. While

doing so, the researcher compares the present incident with previous incidents in the

same and different groups within the same category. This process starts to generate ideas

of the theoretical properties of the category (Seale, 1999). Second, the categories and

their properties are integrated together. That is, the process changes from comparing

incident to incident to comparing incident with properties of the category. Specifically,

the researcher looks for how the properties interact (Seale, 1999). Categories become

integrated with other categories, and properties of categories become integrated together

as well. Third, the researcher begins setting limits to the theory (Glaser & Strauss, 1967).

That is, fewer changes are made to the theory; any modifications that are made are

generally to clarify the logic of the theory. Theoretical categories reach saturation,

meaning that no new information is found about the categories in the data. Also, through

a process of reduction, the researcher begins to formulate the theory with a smaller set of

higher level concepts. By doing so, the researcher starts to achieve parsimony of

variables and scope in the applicability of the theory. Fourth, the researcher begins to

write theory based on the coded data and memos made about the data (Seale, 1999). One

final point that Glaser and Strauss (1967) make is that if theoretical sampling occurs at

the same time as analysis, then integration of the theory is more likely to occur by itself.

Theoretical Sampling

According to Strauss and Corbin (1990), theoretical sampling is "sampling on the

basis of concepts that have proven theoretical relevance to the evolving theory" (p. 176).

Proven theoretical relevance means that certain concepts are thought of as significant

because 1) they are repeatedly present or notably absent when comparing incident after

incident, and 2) through the coding procedures they earn the status of categories (Strauss

& Corbin, 1990). The goal of theoretical sampling is to sample events, incidents, etcetera,

that are representative of categories, their properties, and dimensions, so that they can be

developed and conceptually related. The sampling procedures followed depend on the level of coding one is doing. These levels will be discussed in more detail in the data analysis section. Theoretical sampling continues until saturation of categories is achieved. Theoretical saturation is achieved when 1) no new or relevant data seem to emerge for a category; 2) the category development is dense; and 3) the relationships between categories are well established and validated (Strauss & Corbin, 1990).

Process

Process is the linking of action/interaction sequences (Strauss & Corbin, 1990). This linking is accomplished by noting: 1) the change in conditions influencing action/interaction over time; 2) the action/interactional response to that change; 3) the consequences that result from that action/interactional response; and 4) describing how those consequences become part of the conditions influencing the next action/interactional sequence. Researchers can capture this by tracing out why and how action/interaction, in the form of events or happening, change, stay the same, or regress and with what consequences (Strauss & Corbin, 1990). This process usually unfolds naturally within grounded theory analysis. Identifying process is an essential feature of analysis (Strauss & Corbin, 1990). Once identified, process can be viewed as stages and phases of passage, with an explanation of how movement occurs through those phases; or, process can be conceptualized as a non-progressive, flexible response to changing conditions (Glaser, 1992; Strauss & Corbin, 1998).

Memos and Diagrams

According to Strauss and Corbin (1990), memos are written records of analysis related to the formulation of theory. Diagrams are visual representations of relationships

between concepts. Memos and diagrams are used from the beginning of a research

project and evolve to reflect the conceptual growth of the theory (Strauss and Corbin,

1990). They allow the researcher to keep a record of the various conceptual developments

within the theory. They also allow the researcher to work with ideas through free

association and creativity (Strauss and Corbin, 1990). However, later it is important to

ground these ideas in the data. Memos and diagrams also help to identify holes in ones

thinking and in the theory (Strauss and Corbin, 1990), which can be flushed out using

theoretical sampling. Memos and diagrams change depending on the stage of coding one

is doing, in order to reflect the growth and development of the evolving theory.

Participants

The researcher attempted to recruit participants from MS Clinics in Calgary, Alberta and

Saskatoon, Saskatchewan. However, only participants from the Calgary MS Clinic

agreed to participate. Six parent-youth pairs were recruited from Calgary. Five of the

adolescents were female and one was male. Five mothers and one father also participated.

The children or adolescents were diagnosed with MS by their 18th birthday, but their age

at the time of the study was up to the end of their twentieth year. This allowed for the

individuals diagnosed later on in their adolescence to have developed some experience

living with the disease. One participant turned the age of 21 between the original time of

recruitment and the actual interview, so she was still permitted to participate. A complete

summary of the demographic information about the adolescent participants is presented

in Table 1.The parent-youth pairs were linked, so as to provide richer data of the

experiences of the MS participants. In addition, this allowed the opportunity to compare

Table 1

Summary of Adolescent Participants' Demographic Information

Variable	Participants					
Gender	F	F	F	M	F	F
Age	16	21	19	15	16	14
Age at first symptoms	12	15	16	13	15	13
Age at diagnosis	14	17	17	13	15	13
First symptoms	Vision disturbances Fatigue Memory loss Headaches	Numbness	Balance problems Shakiness	Vision disturbances	Numbness	Vision disturbance
Symptom severity[a]	5	3-4	2-7	2-8	5	4
Frequency of attacks[b]	1	0-2	1-6	2-3	6	2

[a]Severity of symptoms rated by each adolescent on a 10-point scale (1 = not disruptive of everyday functioning, 10 = very disruptive of everyday functioning).

[b]Frequency of attacks = number of attacks per year.

parental perceptions with the perceptions of the children/adolescents with early-onset MS.

Participants were permitted to participate if consent was obtained in writing (Appendix A). In the case of under-age participants, participation was permitted if: 1) consent was obtained in writing from the parents, and 2) consent was obtained in writing from the child/adolescent participating. Participants were told in the cover letter that their participation was completely voluntary and that there would be no repercussions for withdrawal at any point in the study.

Method of Inviting Participants

Potential participants were sent an information letter describing the study and their role in it (Appendix B). In Saskatoon, the MS Clinic staff (i.e., clinic nurse) made initial contact, by phone, with the eligible participants from Saskatoon so as to maintain confidentiality of contact information. If the participants expressed interest in participating, they agreed to release their contact information (i.e., names and phone numbers) to the researcher. During the first recruitment attempt, the only eligible participant from Saskatoon declined to participate. During the second recruitment attempt, the boundaries were extended to all potential participants in Saskatchewan. However, the MS Clinic staff did not contact these participants directly by phone; information letters and consent forms were mailed out by the MS Clinic staff. No response was received from any of these potential participants. Participants at the MS Clinic in Calgary were contacted directly by the researcher since they had already provided consent to participate in any MS-related research through the MS Clinic. Each participant was contacted to set up a time for an interview. The majority of the interviews

took place at the participants' homes. This location was chosen to increase comfort and convenience for the participants. One interview took place at the individual's workplace for the purpose of convenience.

Measures

An interview format was chosen as the data collection method because it allowed opportunity for the participants to talk about the specific issues and experiences that are important to them in regards to the topic. It was used in order to obtain descriptive information of both parents' and the youth's perceptions in regards to the quality of peer experiences and specific examples of peer experiences, and the social behaviours of the youth with MS. The children and adolescents are the experts on the quality of support that they receive from their peers, the type of social experiences they have with their peers, and their own social behaviours. The intention of the interview was to understand the participants' views of their relationships. However, parents can also provide valuable insight into the relationships these youth have with their peers because parents are a primary source of support (e.g., Helsen, Vollebergh, & Meeus, 2000). In addition, parents may be able to provide more objective data about the youth's behaviours than the young individuals themselves. In her review of the literature on children coping with chronic illness, Kliewer (1997) identified that parents were more aware of changes in behaviour. Therefore, interviews were also completed with the parents of the participants with early-onset MS.

It was anticipated that an interview format would provide more detailed, descriptive information than would be available through survey measures. Interviews can also provide information about positive or negative peer relationships unique to

individuals with early-onset MS that may not be detected through formal survey measures, as these measures are often developed for individuals in a healthy population. Finally, through the interview format, it was possible to tap into the unique experiences of individuals with MS that may be difficult to obtain information about through the survey format.

The interview consisted of 10 open-ended questions. A preliminary child/adolescent interview blueprint and a preliminary parent interview protocol, consisting of 14 open-ended questions, were designed and piloted through a number of steps. First, the blueprints were presented to the thesis committee and graduate student colleagues for clarity and focus of the questions. Based on comments from the thesis supervisor, committee members and colleagues, revisions were made to improve flow and clarity of questions, resulting in the 10 open-ended questions. Second, the revised interview protocol was piloted with adolescents without MS in order to determine if the questions were understandable for the target age group. Colleagues and family members were approached for suggestions of potential children and adolescents to participate. Pilot participants included a 15 year old male and a 16 year old female. The final interview protocol (Appendices C and D) was developed based on the pilot process. The questions developed in the interview schedule were followed up by probes, prompts, and open questions which were derived from basic counselling skills (e.g., Tell me more..., Explain..., Give me an example..., How so?). A complete list of the probes and prompts used are provided in Appendix E.

Demographic Information Form

Demographic information, collected through the use of a demographic

information form (Appendix F), was collected for each participant. The primary purpose

of the demographic form was to obtain information about the participants' gender, age,

date of diagnosis, date of first symptoms, frequency of attacks, and severity of symptoms.

Specifically, it was used in conjunction with the interview to obtain expansion and

clarification of the diagnosis information. The demographic form also served as an

engagement tool to assist the researcher to develop rapport with the participants.

Interview Structure -- Child

Introduction

This section attempted to develop comfort for the participant, and was represented

by Items 1 and 2 on the Interview Protocol (see Appendix C). The first question was

designed to be an initial exploration into the participant's experience with MS, especially

around the diagnosis of the disease. The purpose was also to engage with the participant

and encourage him or her to begin telling his or her story. The second question was

designed to gain an understanding of who was in the individual's world in terms of peer

relationships.

Social Support from Peers

This section aimed to explore the nature of the experiences youth with MS have

with their peers. Also, it explored the perceived importance of peers for support and the

quality (e.g., positive experiences vs. negative experiences) of the relationships. This

section was represented by Items 3 and 4 on the Interview Protocol (see Appendix C). In

particular, three groups of peers were addressed: close friends, acquaintances, and the larger peer group.

Social Behaviours

This section attempted to explore the social behaviours of youth with MS. This section was represented by Items 5 to 9 on the Interview Protocol (see Appendix C). In particular, the goal was to explore the role these behaviours may play in the peer experiences of these youth.

Conclusion

This section was intended to provide closure to the interview. This section was represented by Item 10 on the Interview Protocol (see Appendix C). In addition, this section aimed to provide opportunity for participants to share all issues pertinent to them, especially those issues which they may not have had opportunity to share up to this point.

Interview Structure – Parent

The parent version of the interview covered all of the same sections as in the child version: Introduction, Social Support from Peers, Social Behaviours, and Conclusion (see Appendix D). The wording was revised so as to obtain the perspective of the parent or guardian on the relevant issues.

Procedure

Participants were contacted using two different methods, depending on what was approved by the ethics committees of The University of Lethbridge, Faculty of Education, and Calgary Health Region. Participants from the Saskatoon MS Clinic were contacted directly by the MS Clinic Coordinator so as to maintain their confidentiality until the time of their decision to participate. Contact information was to be provided by

the clinic to the researcher upon approval of the participant, or by the participants themselves. Participants in Calgary had already given consent to the Calgary MS Clinic to participate in research. As such, the researcher was able to contact the participants directly. The participants were initially sent an information letter about the study. Then, participants were contacted by phone to set up a time for the interviews. Interviews were done in person.

The purpose of the study was presented in the information letter (see Appendix B). The cover letter identified the following:

1) There is very limited research on the experiences of individuals with early-onset MS. As such, it is important for research to examine the experiences of such a unique group of individuals;

2) The focus of this particular study was primarily on the relationships of individuals with early-onset MS and their peers. The information that participants provided would be important in helping others understand the relationships of individuals with early-onset MS and their peers, and how experiences within these relationships influence how they think and feel. The information provided by participants would be useful in developing programs and services for individuals with early-onset MS, and in educating others who are newly diagnosed with early-onset MS.

3) The issue of confidentiality was addressed in terms of how confidentiality was maintained and what were the rights of the participants.

4) The dissemination of the research results was also discussed.

Data Collection

A total of 13 interviews were completed in the data collection process. Six

adolescent-parent pairs were interviewed separately, resulting in a total of 12 individual

interviews. One follow-up interview served as a small focus-group, at which two of the

original adolescents were present; this was conducted during the verification process.

Each interview took approximately one hour. However interview lengths ranged from 45

minutes to about 1 hour and 15 minutes. The interview lengths seemed to vary because of

the response style of the participant as the same interview protocol was used for each

participant. A semi-structured interview was used. The interview questions varied

depending on the stage of data analysis and theory development. The initial interviews

were based on the interview protocols previously discussed. Additional interview

questions were also used in the latter interviews. According to Glaser and Strauss (1998),

data collection is guided by questions and comparisons which arise through data analysis

and theoretical sampling. Therefore, the interview questions were revised on the basis of

theoretical sampling and to reflect the stages of data analysis. If there was a need for

certain theoretical categories to be flushed out, this was reflected in the interview

questions. A list of additional questions is presented in Appendix G.

Each interview was audio-taped. The audio-tapes were then transcribed using a

word-processor. The word-processed responses served as the raw data for this research.

The trustworthiness of the data was assessed by having 2 participants, in a focus group,

provide feedback on the developing theory. This feedback was then analyzed and

integrated into the research results. Purposeful sampling was used to select the

participants for ethical reasons. In particular, there was concern that some participants

were not emotionally ready to view the results of this study. The purpose of the validity

check was to have participants provide feedback on the fit of the theory with their

individual experiences and stories. Thus, the accuracy of the theory was assessed before

the thesis was completed and before there were any further publications based on this

research.

Data Analysis

Data analysis was derived from grounded theory, which provided a framework for

examining and categorizing interview data into themes. Following transcription of the

data, the analysis involved three steps as follows.

Open Coding

The intention of open coding is to discover concepts (Strauss & Corbin, 1998).

Initially, the first six interviews (i.e., 3 adolescent-parent pairs) were coded line-by-line.

These codes were recorded directly on the manuscript. The concepts identified were

named because of the imagery or meaning they evoked, or the name may have been taken

from the words used by the participants, and should be context specific. A significant

number of unrelated statements were acquired in order to identify initial themes in the

data. According to Strauss and Corbin (1998), it is necessary to compare these discrete

parts for similarities and differences. These initial codes were grouped according to initial

categories arising through each interview question. Initial memos were also developed

and recorded in both a notebook and a word-processing document. The next six

interviews (i.e., 3 adolescent-parent pairs) were coded paragraph by paragraph, with the

major ideas being identified. If a major idea seemed to be connected with the concepts in

previous data, this major idea was analyzed in more detail. At this point, events,

happenings, objects, and actions/interactions that were found to be similar in nature or meaning were grouped under more abstract concepts called categories (Strauss & Corbin, 1998). According to Strauss and Corbin (1998), the terms used to label categories should classify the items in the category and explain what kind of action is occurring. The data was coded into as many categories of analysis as possible. Once a category was identified, it was developed further by identifying the properties and dimensions. This was recorded within memos in a word-processing document. Strauss and Corbin (1998) defined properties as "the general or specific characteristics or attributes of a category" and dimensions as representative of "the location of a property along a continuum or range" (p. 117). By analyzing these properties, patterns in the data were identified. This initial stage of open coding helped to discover participants' views and compare data from different people on a similar subject.

Axial Coding

In the second stage, axial coding, the researcher used the most frequently appearing initial codes to sort, synthesize, and conceptualize the data. Specifically, categories were related to subcategories based on their properties and dimensions. Subcategories denote more specific information about a category, like when, where, why, and how a phenomenon is likely to occur (Strauss & Corbin, 1998). The data was then categorized more precisely under conceptual codes, and the fit was checked with the emerging theoretical framework. The researcher looked for answers to questions like why, how come, where, when, and with what results to discover the relationships among categories. Additional codes developed during this time and replaced previous codes which did not fully describe a phenomenon. Through this process, conditions, or sets of

events or happenings that created the situations, issues and problems related to a phenomenon were identified. The theory developed as different categories and their properties become integrated. That is, relational statements were developed about the concepts identified. These themes were a guide to new data collection. With each new interview, the categories were coded and compared to the ones in interviews before it. If new categories arose in the data, then the previous interviews were reanalyzed to check for the presence of those categories. This process was recorded in memos both in a notebook and a word-processing document. Several diagrams were also developed as an attempt to understand the developing theory.

Selective Coding

In the selective coding stage, previously identified codes were compared and contrasted for common themes. This allowed opportunity to fill out the theoretical categories and define the properties of the categories (Charmaz, 2002). Categories were also integrated and refined in order to create a concise theory. According to Strauss and Corbin (1998), the first step of integration was to identify a central category which represents the main theme of the research. This was identified and the other categories were then related to this central category. Theoretical links were identified between categories and a smaller set of higher level concepts were developed. These final themes or theoretical categories best explain what was happening in the research study. The interconnection of categories was then explained through a diagram, which became the initial theoretical hypothesis. The researcher kept seeking data until the categories were saturated, filling in underdeveloped categories and narrowing excess ones (Strauss & Corbin, 1998). Data saturation occurred when no new information was found. The

researcher then validated the theory by checking it against raw data and by presenting it to participants for their feedback.

Trustworthiness in Qualitative Research

Ensuring rigor and trustworthiness in qualitative research is a critical component of the research process. Trustworthiness addresses the issue of how a researcher can convince the audience that the research findings are worth paying attention to (Lincoln & Guba, 1985). Even though qualitative research is often criticized by researchers from the positivist paradigm (i.e., quantitative research), many methods have been developed to address the credibility of this type of research (Shenton, 2004). In their seminal work, Lincoln and Guba (1985) provide a framework for ensuring the trustworthiness in qualitative inquiry.

The framework developed by Lincoln and Guba (1985) identifies critieria within qualitative research which parallel the criteria in quantitative research for evaluating rigor or validity of the research. These criteria include: 1) credibility (parallel to internal validity); 2) transferability (parallel to external validity); 3) dependability (parallel to reliability); and 4) confirmability (parallel to objectivity) (Morrow, 2005). Researchers (Lincoln & Guba, 1985; Morrow, 2005; Shenton, 2004) have identified numerous strategies which can assist the researcher in fulfilling each of these criteria in the research process. In addition, grounded theory incorporates many of these techniques for achieving each of these criteria within its methodology. However, a review of the specific strategies implemented in this study will be presented here. The first criteria, credibility, was achieved in this study by implementing well established research methods (i.e., grounded theory methods), developing familiarity with the culture of the participants,

triangulation, peer debriefing, negative case analysis, iterative questioning and the use of probes, debriefing sessions with the researcher's supervisor, maintaining a reflective commentary (i.e., memoing), member checks, and thick descriptions of the participants' experiences. The second criteria, transferability, was achieved through the detailed descriptions of the researcher's previous experience with the topic, the research context, processes, and participants so that the reader can decide how the findings of this study may transfer. The third criteria, dependability, was achieved by keeping an audit trail of the decisions made in regards to all aspects of the research activities (e.g., influences on data collection and analysis; how data was gathered). Finally, the fourth criteria, confirmabilty, was also achieved through the use of an audit trail. Each of these criteria, and the strategies used to fulfill them, are presented in more detail in the works by Lincoln and Guba (1985), Morrow (2005), and Shenton (2004). By fulfilling each of these criteria within the research process, the research can unsure the trustworthiness of this qualitative research study.

Compliance with Human Subjects Research Protocols

Confidentiality of Information

Confidentiality of information was addressed in a number of ways. First, personal contact information of participants was released to the researcher, by the MS Clinics, only upon consent of the participants. Second, all participants were assigned an identification number (ID #) which was used when coding the data. The ID #'s were a three digit number. The first number represented if the participant was an adolescent or a parent (e.g., 1 = adolescent, 4 = parent). The second number represented the participant's gender (e.g., 0 = female, 1 = male). The third number represented the parent-youth pair

(e.g., 1 = first pair, 2 = second pair, etc.). These ID #'s were entered into the computer and all analyses were based on ID #'s, not on names. Data was reported in the aggregate form, such that no individual child or case was discussed, but the data was discussed as a whole. When quotes or examples were used from the transcribed interview data in the written report, names were omitted or changed to pseudonyms when necessary, and any other potentially identifying information was changed. For example, personal pronouns (e.g., he, she) were randomly assigned to protect the anonymity of the respondents. Only the researcher and the research team had access to participant information, in order to prevent unauthorized collection, use or disclosure of participants' personal information. All interview data were stored in a file in a secure place at the researcher's home, where they will be kept for five years.

Participants Access to Results

The consent letter informed participants that they may contact the researcher if they would like to receive feedback about their data. The consent letter also informed participants that they would be given an opportunity to view conclusions before public release of the research (i.e., they were asked at the end of the interview if they would like to be contacted by the researcher at the end of the study to view results). Upon completion of the study, research findings were made available through The University of Lethbridge Library. Hardcopies of the results were available to participants upon request and summaries of the study were sent to participating MS Clinics. The results may also be used in future presentations and/or publications.

Conclusion

This chapter discussed the methodology used for this thesis. As mentioned, the methodological approach was based on grounded theory. Interviewing was the primary source of data collection. Constant comparison analysis was the primary tool for data analysis and theory development. This study also conformed to the requirements of Human subjects research protocols. Chapter Four presents the results of this thesis. Chapter Five elaborates on the contributions of these results to existing literature. Chapter Six then discusses the implications and limitations of this study.

CHAPTER 4: DATA ANALYSIS

The purpose of this chapter is to describe the analysis of data and the subsequent

generation of grounded theory. The objective of this study was to describe the nature of

peer relationships and social behaviours in the psychosocial development of children and

adolescents diagnosed with early-onset Multiple sclerosis. Data collection was

accomplished through the use of semi-structured interviews. The transcripts from the

interviews were then drawn on as the source of data for analysis. Grounded theory

methodology was used to code and analyse the data, and subsequently develop the

grounded theory.

Development of Categories and Themes

Data Analysis Procedures

Strauss and Corbin (1998) suggest that the first step in grounded theory data

analysis is microscopic analysis of the data. This is line by line analysis, usually

performed to develop initial categories and suggest possible relationships between

categories. As such, this initial stage is a combination of open and axial coding. The

researcher recorded memos to summarize the categories and themes and brainstorm

possible relationships between them. In addition, diagrams were drawn to conceptualize

the potential relationships between categories.

Once the first three sets of interviews, comprised of three adolescent interviews

and three parent interviews, were coded line-by-line, they were analyzed by interview

question. The interview questions were not always asked in the same order as the

researcher followed the lead of the participant, yet the same interview questions were

always asked. If the participant brought up the topic that would be covered in an

interview question, the researcher then posed the appropriate interview question. In order to make sense of the initial data it seemed suitable to organize it based on interview questions. The coding began at a descriptive level which focused on detail and not interpretation. Then coding moved to a conceptual level, which allowed the researcher to make sense out of the data by organizing it into classifications or categories (Strauss & Corbin, 1998). This was accomplished by comparing the participants' responses to one another.

The second set of interviews, comprised of another three linked adolescent-parent sets, were then coded paragraph by paragraph. This technique was used as initial categories were already developed and the researcher wanted to code the data in relation to them. This broader form of analysis also proved useful for refining the names of categories. If a new concept seemed to arise in this set of data analysis, then the paragraph was analyzed in more detail through line-by-line analysis. These new codes were then added to the previous list of codes and the previous interviews were re-examined for these codes. Throughout this process the researcher continued to record memos and diagrams about the data.

The final stage in the analysis process was theorizing. Strauss and Corbin (1998) describe theorizing as a process of constructing a logical and systematic scheme to explain the relationships within the data. At this point, the researcher moved back to a more detailed analysis of the data in order to ensure the properties and dimensions of the categories were fully developed. If it seemed that some areas were lacking, then theoretical sampling was used in the final interviews in order to obtain this data. Data collection, coding, and theorizing continued for several months.

Initial Categories from Interview Questions

The purpose of this section is to explore the themes and categories which arose

from the data in the first three sets of interviews . Responses from both the adolescents

with MS and their parents were combined to develop the list of codes and themes for

each interview question. As the goal of using both adolescents and parents as sources of

data was to develop a more comprehensive understanding of the experiences of these

adolescents, it seemed appropriate to combine the data for analysis. When the two

perspectives were kept separate, it was difficult to understand the social processes taking

place. On the one hand, the adolescents seemed to be able to provide rich data about their

experiences with their peers, but provided less detail about their own psychological

experiences. Parents, on the other hand, provided more detailed descriptions of the

psychological experiences of the adolescents with MS, but seemed somewhat unaware of

the adolescents' peer experiences. However, when the two perspectives were combined,

the researcher was able to gain a greater understanding of the overall psychosocial

experiences of these adolescents. The following is a summary of the results from the first

stage of the analysis process.

The first interview probe was "Tell me about your diagnosis of MS." Participants

described this experience in many ways. One way that participants responded was to

describe their initial symptoms. These symptoms included vision disturbances, fatigue,

loss of memory, numbness, dizziness, and loss of balance. Participants also went into a

more detailed explanation of their symptom experience. This included discussing the

frequency of attacks, severity of attacks, and physical limitations. A second way

participants responded to this question was to describe their experience with helping

professionals. These descriptions included the types of helping professionals participants encountered and the experiences they had with those professionals. A third way participants talked about their diagnosis was to describe the process of diagnosis. This included descriptions of the series of tests undergone and their experience of diagnosis as a process of elimination. Fourth, participants responded to this interview question by describing the changes in behaviour and attitude of the adolescent with MS. This included both a description of what the changes were (e.g., nervousness, hopelessness for future, fear of attention, facing challenges), and why they occurred (e.g., diagnosis as a challenge to identity, lack of knowledge about the disease). Fifth, participants described the diagnosis of MS through experiences with medications. This included learning about medications, and their thoughts and feelings about the medications. Sixth, participants talked about their diagnosis by describing how they revealed their diagnosis. Specifically, this focused on the question "to tell or not to tell?" Finally, parent participants often talked about their adolescent's diagnosis by sharing their own reactions to changes in the adolescent. The most common response reflected how the parent attempted to protect the adolescent from the disease experience.

The second interview item invited participants to: "Describe for me your experiences with the individual(s) in that network/group since your diagnosis." This question was further broken down into three parts: a) close friends, b) acquaintances, and c) general peers. First of all, there was a theme that arose from participants across all these groups. Participants described this as a change in peer relationships, whether it be a loss of friendships, a strengthening of friendships, or creation of new friendships. This change seemed to affect those initially impacted by the diagnosis. Participants also

explained that this occurred because of the maturity of the adolescent, a change in choice of friends, and a need for self-preservation.

When asked specifically about experiences with close friends, one of the themes that arose was a change in friends. Specifically, participants described a shift to a smaller group of close friends. Some of the explanations given for this included letting go of negative relationships, holding onto those one could trust, and lack of control over disease. Second, participants described the initial reactions of close friends to the diagnosis. Some of these reactions included fear, disbelief, popularity loss, and support. Third, participants described the reactions of the adolescent with MS to friends after the diagnosis. Some of the reactions mentioned included withdrawing, difficulty sharing experiences, changing mood, changing shared activities, expecting negative responses from others, or no change at all. Fourth, participants described having a small group of reliable and loyal friends. Some of the characteristics given for this group included effective support, active involvement with disease, and being overprotective.

When asked specifically about experiences with acquaintances, participants described several themes. First, participants described why not all acquaintances were told of the MS. These responses included fear of others' responses, wanting to protect others, and wanting to avoid pity. Second, participants described changes in acquaintances' behaviour since the diagnosis (e.g., avoiding, reassuring, no change). Third, participants described changes in the attitude and behaviour of the adolescent with MS. Some of these changes included anxiousness, withdrawal, and appreciation. Fourth, some participants described communication challenges with these peers. Fifth, some

participants described a loss of relationships. Specifically, they described the reasons for the loss, including loss of popularity and being treated differently.

When asked specifically about experiences with the general peer group, participants described rarely disclosing to these individuals. They indicated that the purpose of this was to maintain privacy. Second, participants described the reactions of general peers to the MS. Some of these reactions included symptom misperceiving and unexpected helping. Third, participants described the reactions of the adolescents with MS to their general peers. The most common reaction was withdrawing.

The third interview question related to the quality of each of the previously mentioned peer groups: "How important is this relationship to you?" This question was dropped from the interview protocol following the third set of interviews. This question did not offer any new or valuable information that was not already shared in the previous question. Participants consistently described close friends as being important for support. Acquaintances and general peers were described as transitory and rarely important to the adolescents' experiences.

The fourth interview question was "Have you noticed any differences with fitting in with your peers since your diagnosis?" Participants responded to this question by describing the changes in the behaviour of the adolescent with MS. For example, some respondents identified that the adolescent would withdraw. Sometimes this was just at first after the diagnosis, and for others it was on going. Other participants identified changes in the adolescents' socialization patterns (e.g., may be disease dependent, working to maintain support network). Still other participants identified no changes in the adolescents' behaviour.

The fifth interview question asked, "Do you act the same way or differently?" One way participants responded was to describe a change in behaviour of the adolescent, such as withdrawing, fighting more, and faking that everything is fine. A second way participants responded was to describe a change in attitude of the adolescent. For example some expressed more negativity, insecurity, loss of faith, or greater maturity. A third way participants responded was to describe no changes in behaviour or attitude after diagnosis.

The sixth interview question asked was "Do your friends act the same way or differently?" Some participants responded to this question by describing supportive responses from friends. For example, some friends were reported to be more protective and provide active support (e.g., helping with notes at school). Other participants responded by describing the cautious reactions of peers to the MS (e.g., limiting recreational activities). Yet another theme arising from this question was negative responses from friends. For example, some participants described friends responding by avoiding or ignoring the adolescent. Finally, some respondents described a change in peer relationships, whether it be redefining of old relationships or developing new relationships with friends who are disease-accepting.

The seventh interview question asked was "How do you react to your peers when they ask questions about your MS?" Some participants responded to this by describing an openly descriptive response style. This was further expanded on by participants by explaining the benefits of an open approach (e.g., increased self-confidence). On the other hand, other participants described not freely offering information about the MS.

This was further expanded on by explaining the negative consequences of disclosure (e.g., negative reactions from peers).

The eighth interview question was "How do you express your MS experience to you peers? Most participants answered this question by describing being open with close friends to obtain support. However, participants also described a withholding of their experiences of MS. For some this was dependent on the level of trust, and therefore the MS was not shared with general peers and some acquaintances. For others, the MS diagnosis was withheld out of uncertainty for the future or fear of others' reactions.

The ninth interview question was an open question for participants to share anything else they had not already had the opportunity to share. Some of the responses from participants included the role of family in the MS experience, change in diet due to diagnosis, support received from drug companies, and the importance of being connected with MS resources to develop acceptance.

The initial interview questions were designed to elicit responses to the researcher's two sub-questions. It became a challenge to focus just on the themes which arose within each interview question. Participants would address the same issue during several of the questions. As such, the researcher looked across interview questions for broader categories. This approach allowed the researcher to obtain a greater understanding of the experiences youth with MS had with their peers. Despite the rich descriptions of the adolescents' experiences with MS, however, the responses did not seem to clearly align with the two research sub-questions. Consequently, the researcher struggled to make sense of the reactions of the adolescent with MS.

The researcher then took a break from data collection and analysis in order to process the themes and categories which had already arisen. After a brief time away from the data, the researcher made a connection between some of the experiences of the adolescents with MS and a grief process. It had been difficult to categorize the data without the grief component. It was necessary to consider the participants' rich descriptions, especially about peer relationships, in light of their grief reactions in order to really understand their experiences. This became a crucial piece in developing the new grounded theory.

A second literature review on grief in chronic illness was conducted. The literature review helped the researcher to gain an understanding of the unique grief experiences undergone by individuals with chronic illnesses. Also, it created a new opportunity for theoretical sensitivity which broadened the researcher's perspective on the data. It was not until the connection to grief was found that all the data seemed to fit into place. A summary of this secondary literature review follows.

The Experience of Grief and Loss in Chronic Illness

According to Strauss and Corbin (1990), the purpose of grounded theory is discovery, and therefore a complete knowledge of potentially relevant literature beforehand would hinder this process. Instead, they recommended that the researcher goes back to the literature only after a category has emerged in the data. The grief experience of adolescents with MS emerged as a core category in the grounded theory developed from the present study. The grief process seemed to be significant in understanding the psychosocial experiences of individuals with early-onset MS. In addition, it provided a context for understanding the role of peer relationships in the

overall wellbeing of these individuals. As this concept was not addressed in the initial literature review, it was deemed necessary to do a secondary literature review.

Traditional View of the Grief Process

One of the originators of grief research was Dr. Elisabeth Kübler-Ross (1969). Kübler-Ross presented some of the original work on the concept of grief through her research on death and dying. Her model was comprised of 5 stages which the individual experienced in sequence. The stages could be experienced over varying lengths of time, and sometimes concurrently. She labelled the first stage 'denial and isolation.' Initially this denial is healthy, acting as a buffer from the painful situation and an escape from overwhelming emotion. This can become problematic, however, if people continue to use denial to escape the reality of the situation. The second stage was labelled 'anger.' Individuals in this stage felt emotions like anger, rage, envy and resentment. The anger was often projected onto anyone and anything in the individual's environment. This anger was frequently taken personally by the support system when in fact it originally had nothing or very little to do with the target individual. Kübler-Ross labelled the third stage 'bargaining.' During the bargaining stage, the individual made a promise, as a reward for good behaviour, in hopes that it would postpone the inevitable. The fourth stage was labelled 'depression.' Kübler-Ross described a feeling of deep loss at this stage, which ultimately resulted in depression. However, she went further to distinguish between two types of depression. The first type is a reactive response to the loss(es) experienced and is often associated with guilt and shame. The second type is a preparatory depression, in consideration of impending losses. The fifth and final stage of the grief process was identified as acceptance. An individual reaches this state once he or

she has had an opportunity to work through the overwhelming emotions of the previous stages. Kübler-Ross described this final stage as almost being devoid of feeling. Together these five stages made up Kübler-Ross' model of the grief process.

Though this approach offers valuable insight into the grief experience, the concept of stages is controversial. First of all, the idea of stages seems to imply a certain passivity as one merely passes through the various stages. It does not suggest any opportunity for the individual to actively work towards change. Second, the idea of stages implies a set sequence of experiences. As such, it does not seem to account for individual variation in the grief experience. For example, it does not recognize that not everyone will experience the same emotions, or respond with the same behaviours, at the same time, or in the same sequence. As a result of these inadequacies, other theories of grief have since been developed which seem to capture the unique, individualized experience of grief.

Contemporary Views of the Grief Process

Four Tasks of Mourning

A contemporary view on grief was presented by William Worden (2002) in his book *Grief Counseling and Grief Therapy*. Worden viewed the grief experience as a fluid process made up of four tasks: 1) To accept the reality of the loss; 2) To work through the pain of grief; 3) To adjust to an environment in which the deceased (loss) is missing; and 4) To emotionally relocate the deceased (loss) and move on. Worden emphasizes that these tasks can be revisited or reworked over time. In addition, various tasks can be worked on at the same time, recognizing the unique experience of each individual mourner.

Worden (2002) suggests that one task of the grief process is to accept the reality of the loss. This implies that the individual must come face to face with the reality that the loss has occurred and is now gone. Someone who is not successful in completing this task is denying the loss. Worden (2002) suggested that the denial is generally in regards to one of the following: 1) facts of the loss; 2) meaning of the loss; and 3) irreversibility of the loss. Someone who is successful in completing this task will demonstrate acceptance, both intellectual and emotional.

Another task of the grief process identified by Worden (2002) is to work through the pain of grief. Individuals will experience different intensities of pain, and will feel the pain in different ways (e.g., sadness, anxiety, anger, guilt, loneliness). Worden (2002) argued that it is impossible to lose something you have been deeply attached to without experiencing some level of pain. The opposite of this task is not to feel. This is typically represented by a denial of feelings, which could eventually lead to a breakdown resulting in depression. Successful completion of this task results when the individual works through their pain experience.

One more task of Worden's (2002) grief process is adjusting to an environment in which the deceased is missing. There are three areas of adjustment: 1) external adjustment: how the loss affects one's everyday functioning; 2) internal adjustment: how the loss affects one's sense of self; and 3) spiritual adjustment: how the loss affects one's beliefs, values, and assumptions about the world. This task is halted when the individual does not adapt to the loss. This may be manifested by the individual promoting his or her own helplessness, not developing coping skills, or withdrawing from his or her social environment.

The final task of the grief process that Worden (2002) identified is to emotionally relocate the loss and move on. In terms of death, this task is generally understood in terms of finding a way to memorialize the loss but still continue on. In terms of a loss like chronic illness, the individual may find ways to remember life before the onset of the disease but still move on. This may be accomplished by helping the individual notice the things in life that are still open to the individual to take part in. Incompletion of this task was labelled by Worden (2002) as 'not loving.' He clarified this by saying that one holds onto past attachments rather than going on and forming new ones. In terms of loss due to chronic illness, this may be represented by the individual holding onto the way life was before the chronic illness and unwilling to develop a new sense of self with the illness.

Manifestations of Normal Grief

Normal grief can be manifested in many ways: emotionally, cognitively, and behaviourally. Some of the commonly identified feelings associated with grief include sadness, anger, guilt, anxiety, loneliness, fatigue, helplessness, shock, yearning, and numbness (O'Toole, 1995; Worden, 2002). Some of the common cognitions connected with grief include disbelief, confusion, and preoccupation (O'Toole, 1995; Worden, 2002). Finally, some of the behavioural experiences associated with the grief process include sleep disturbances, appetite disturbances, absentminded behaviour, social withdrawal, avoiding reminders of the loss, sighing, crying, and restless over-activity (O'Toole, 1995; Worden, 2002). Manifestations of acceptance of the loss may include hope for future, feeling at peace with the past, increased sense of inner strength and competency, reconnection with others, reorganizing life and learning new skills

(O'Toole, 1995). Though there are common tasks in the grief process, the actual experiences can be quite varied.

Grief in Childhood and Adolescence

Grief and development. According to Worden (2002, 1996), the four tasks of mourning are applicable to adults, adolescents and children. However, when considering the grief experience of children and adolescents it is important to consider the developmental level of the individual. The developmental tasks of the child or adolescent are likely to impact the grief experience by making some tasks more challenging than others, or for adults. The grief process may actually be extended over a longer period of time because of the ongoing developmental tasks. For example, Erikson (1985, 1968) argued that the period of adolescence is important in developing self-esteem, a sense of belonging, and a feeling of self-sufficiency and control. The experience of loss can be manifested by the adolescent withdrawing from peers, subsequently challenging their ability to belong. Loss may also influence the adolescent to feel different, or "feel like an odd kid" (Worden, 1996), challenging their developing self-esteem. Therefore, children and adolescents face the difficult challenge of working through grief while it is complicated by important developmental tasks. Some manifestations of grief for children and adolescents include lower self-esteem, less control over what happens to them, more withdrawal, anxiety, depression, social problems, and school problems (Worden, 1996).

Role of peers in grief process. This thesis addressed the role of peer relationships in the psychosocial development of youth with MS, and so it seemed important to examine the role peers could play in the grief experience of children and adolescents. Worden (1996) studied children and adolescents who experienced the loss of a parent,

and the subsequent impact on relationships with peers. Some children reported spending more time with friends immediately after the sudden loss of a parent. However, others reported spending less time, sometimes as a result of feeling more depressed. Some children also described feeling stigmatized by the loss. As a result, they seemed to want to hide the loss to avoid being teased or feeling different. There were also reports by children about being teased and taunted by peers regarding the loss. According to Jarratt (1994), children can be really cruel to one another. However, she argued that they can also demonstrate a desire and capacity to help the grieving peer if someone explains the situation to them and provides ideas on how to be supportive. In addition, Worden (1996) found that friends were seen as a positive influence in the grief process by providing support and understanding. Having a friend who had a similar experience was one important factor in gaining support. Interestingly, the individuals who communicated with peers about the loss had higher self-esteem and self-efficacy than those children who did not talk with friends about the loss. This highlights the influential role peers can have on the grief process.

Worden's model of the grief process seems to be a comprehensive model which applies to both adults and children. Specifically, it addressed the limitations of Kübler-Ross' theory of grief by developing a model based on tasks of mourning as opposed to stages. This change acknowledged the individual differences in the experience of the grief process and gave the individual a sense of control over the process. Although there are many applications of Worden's work to grieving associated with loss due to chronic illness, there are also several limitations. For example, a limitation to the model of grief presented by Worden is that it only addressed concrete losses (e.g., death). Specifically, it

does not address the unique type of loss experienced with the diagnosis of a chronic illness. Further, it does not account for the variation in the grief experience because of this type of loss. For example, it does not recognize the unpredictability of a disease like MS with its common relapses. In addition, it does not recognize the additional losses (e.g., identity, hope for future, friendships) that could be experienced as the result of a potentially debilitating disease like MS. Finally, it does not acknowledge the unique experience related to a loss of self as opposed to a loss of someone or something outside of one's self. It is important to address how the grief process is impacted by chronic illness in order to fully understand the psychosocial experiences of adolescents with chronic illness.

Grief and Chronic Illness

There is a paucity of literature addressing chronic illness and the grief process. Literature describing the grief experience of children and adolescents with a chronic illness is almost nonexistent. Nonetheless, the present study identified that it is a relevant and significant concept in the psychosocial development of adolescents with MS. As such, it is important to review what literature there is available on the topic. Most of the literature that is available addresses grief in individuals with terminal illness. Though this may shed some light on the unique experiences associated with illness, terminal and chronic illness are distinctly different in that the former has a foreseen conclusion, whereas the latter does not. The resulting grief experience is likely to be tangibly different. As a result, a review of the contemporary literature which specifically addresses chronic illness and grief will be presented, followed by a more in depth look at three relevant theories: ambiguous loss, cyclic loss, and chronic sorrow.

Variations in Loss

In general, it is not the grief process itself that is substantially different between someone who has experienced a loss from chronic illness and someone who has experienced loss from death. However, the type of loss does impact the intensity, duration, and movement through the grief process. Werner-Beland (1980) argued that grief related to the loss of self through chronic illness is unique. The feelings of loss may diminish over time; however frequent events can remind the individual of the loss (e.g., relapse, facing new challenges in developmental stages). As Werner-Beland (1980) stated, "grief raises its ugly head each time the illness or disability becomes conspicuous or when it significantly interferes with hoped-for goal achievement" (p. 4).

Several variations in the grief experience for individuals with chronic illness have been identified in contemporary grief literature. For example, these individuals seem to be more prone to denial (Kahn, 1995). Kahn (1995) suggested that the denial will decrease with time, but will never be completely abandoned as it is necessary in maintaining hope for a relatively normal life. However, prolonged and extensive denial can be a risk to treatment compliance and social support. Previous research has also demonstrated that an anger response is more prominent in individuals with chronic illness (Kahn, 1995; Sharoff, 2004). This response may arise when individuals realize their future plans are threatened. However, maladaptive anger tends to get targeted at the same people who are necessary for support (Kahn, 1995). Chronic illness also presents a greater threat to self-esteem and identity (Kahn, 1995; Sharoff, 2004; Werner-Beland, 1980). These individuals face the challenging tasks of realizing potential changes in life roles, coping with stigma, finding a balance between dependence and independence, and

redefining who they are (Goodheart & Lansing, 1997; Kahn, 1995; Sharoff, 2004; Werner-Beland, 1980). This experience may give rise to anxiety and depression (Kahn, 1995). Another unique aspect of grief for individuals with chronic illness is struggling with their own grief experience while others around them are also mourning the loss (Werner-Beland, 1980). As a result, chronically ill individuals may worry about how others' are impacted by the loss of health and how they are coming to terms with the loss. For some, this may result in them attempting to hide their illness and their grief in order to protect others. It has been demonstrated that chronic illness can have a distinct impact on the experience of grief.

Ambiguous Loss

The theory of ambiguous loss was originally developed in the mid-1970's to explain the grief and loss experience of families who's fathers were distant and absent (Boss, 2004). It has since been adapted to explain loss and grief in many other situations, including individuals with chronic illness (Boss & Couden, 2002). Ambiguous loss is defined as "a situation where a loved one is perceived as physically present while psychologically absent, or physically absent but kept psychologically present because their status as dead or alive, dying, or in remission, remains unclear" (Boss & Couden, 2002, p. 1352). In regards to chronic illness, Boss and Couden (2002) argued that illnesses that are challenging to diagnose and have no cure are filled with ambiguity. Consequently, if the individual emotionally withdraws, he or she becomes emotionally absent (Boss & Couden, 2002). According to Boss and Couden (2002) ambiguity may have important implications for the grief process. When the progression of the illness is not known, the individual may deny it even exists. Also, without the typical markers of

loss, the individual may not receive permission or support to grieve. The ambiguity around the illness may also cause the individual to question his or her view of a fair world. The challenge for these individuals lies in determining how to move forward when ambiguity blocks understanding.

The theory of ambiguous loss enhances Worden's perspective on grief by considering some of the unique aspects of loss from chronic illness. It brings greater clarity to grief in chronic illness as it takes into consideration the ebbs and flows of the illness and how these contribute to the grief process. It also addresses the ambiguous experience of living with a chronic illness and how that may complicate the grief process. However, this theory was typically used to explain the loss of someone who is physically missing (e.g., lost soldiers) or psychologically missing (e.g., Alzheimer's disease) (Boss, 2004). As a result, this does not seem to be an all-encompassing explanation for the loss experienced by an individual with a chronic illness. For example, these individuals may not necessarily withdraw emotionally or psychologically as in the latter situation. Thus, while the theory of ambiguous loss contributes to the understanding of grief in chronic illness, it still only partially explains this unique phenomenon.

Cyclic Loss

Lewis (1983) originally presented the idea that the grief experienced by individuals with chronic illness is cyclical in nature, as demonstrated by "so many little dyings along the way" (p. 8). This cyclic model of grief assumes that with each little dying or loss, the individual goes through some experience of the grief process. Some examples of the possible losses she identified include: good health, independence, sense of control, privacy, modesty, body image, relationships, social roles, social status, self-

confidence, life style, plans or dreams for the future, idea of immortality, familiar daily routine, sleep, and leisure activities. Each of these can impact the individual's identity, self-esteem, and self-worth, which may also be lost to some extent during the process. Lewis (1983) argued that it is important to grieve these losses in order to integrate the illness into one's psychological perspective and so that it is no longer a painful reminder of what once was. Therefore, the theory of cyclical loss is significant in understanding the grief process for individuals with chronic illnesses.

More recent literature addressing cyclic loss has applied this model to families with children with chronic or developmental disabilities (Worthington, 1994). Worthington (1994), argued that the family, as a system, goes through "a series of recurring, sometimes predictable, stresses that force the family through a series of continual adjustments" (p. 299). Even though this presentation of the model gives a much needed perspective for understanding the grief experiences of the family system, it still overlooks the unique experiences of the individual child. There seems to be a substantial gap in the literature addressing how this cyclic model of grief may apply to children and adolescents with disabilities like MS.

Chronic Sorrow

Chronic sorrow was originally described by Olshansky in 1962 (as cited in Burke, Hainsworth, Eakes, & Lindgren, 1992) to explain the grief in parents of children with mental deficiencies. Since then, several researchers (Burke, Hainsworth, Eakes, & Lindgren, 1992; Eakes, Burke, & Hainsworth, 1998; Lindgren, Burke, Hainsworth, & Eakes, 1992) have refined and operationalized the definition of chronic sorrow as a pervasive sadness that is permanent, periodic, and progressive in nature. The model these

researchers developed suggests that the individual goes through a loss experience, which is ongoing in nature, resulting in a natural grief reaction. However, the continual presence of this loss experience holds the individual in "an emotional bondage that does not permit reestablishment" (Burke, Hainsworth, Eakes, & Lindgren, 1992, p. 232). Consequently, the individual cycles through the grief and sorrow with each trigger (e.g., ongoing, related losses). The advantage of this theory, is that it seems to incorporate the cyclic and ambiguous nature of grief from chronic illness into one model. In addition, the application of this theory has been expanded to individuals with a variety of losses (e.g., chronic illness), as well as to their families. However, the researcher was unable to find any literature which studied the use of this model with children with disabilities.

In conclusion, it would seem that the grief experience of adolescents with chronic illness is distinct from the typical understanding of grief. Adolescents will likely go through the same grief process, with the same four tasks as outlined by Worden (1996, 2003). However, it will be impacted by age through many developmental tasks, and by illness through the unique experience of a loss of self, the ambiguity of the illness, and the numerous secondary losses which accompany a loss of health. It would be useful to develop a new model of grief which incorporates each of these characteristics in order to clarify the grief experience of adolescents with chronic illness.

The Grounded Theory

The findings of this study are presented in a theoretical model intended to explain the experiences of youth with MS, the role of peer relationships in those experiences, and the contribution of the social behaviours of these adolescents to their peer relationships. The themes and categories that generated the theory were constructed through a process

of constant comparison, conceptual ordering and theorizing, as described by Strauss and

Corbin (1998). The grounded theory was presented to a theoretical group, consisting of

two adolescent participants, to assess trustworthiness by testing if the substantive coding

and category labels were an accurate representation of their experiences.

The grounded theory generated from the data is presented in Figure 1: The Grief-Peer

Dynamic Theory. As outlined in the schematic, two core categories and nine sub-

categories were identified from the interview data. The two core categories were labelled

'the grief experience' and 'relationship dynamics'. Although they are presented as

distinct categories, they have reciprocal impact on each other. The three sub-categories of

'the grief experience' were labelled: a) loss experiences; b) manifestations of grief; and c)

manifestations of acceptance. The six sub-categories of 'relationship dynamics' were

labelled: a) medication-peer tug of war; b) shift in friendships; c) supportive

relationships; d) dealing with others' worry; e) talking about MS; and f) acting as if. Each

of these categories and sub-categories consist of themes and dimensions that emerged

from the data.

In general, the theory hypothesizes that psychosocial development occurs within

the context of 'the grief experience'. The development of the adolescents with MS is

demonstrated in their movements through the grief process. As the adolescents

experience losses, they move through the cyclic grief process. In doing so, they may learn

ways to cope with the various social, emotional, and behavioural manifestations of grief

and transition towards acceptance. However, they may also remain stagnant in their

experiences of grief, halting movement through the grief process. Peer relationships,

represented by 'relationship dynamics' are suggested to play both direct and indirect roles

The Grief Experience

Loss Experiences

Manifestations of Grief

* Denial
* Anger
* Depression
* Anxiety
* Withdrawal
* Sadness
* Self-doubt
* Isolation

Grief

Acceptance

Manifestations of Acceptance

* Learning to cope
* Facing challenges
* Prioritizing
* More appreciative
* Positive perspective
* Future-focused

Dynamic Relationships

* Medication-Peer Tug of War
* Supportive Relationships
* Shift in Friendships
* Dealing with Others' Worry
* Talking about MS
* Acting as If...

Figure 1. The Grief - Peer Dynamic Theory

in 'the grief experience' and subsequent psychosocial development. Sometimes the 'relationship dynamics' are shaped by the adolescents' grief experiences. However, other times, peer relationships mould the adolescents' experiences of grief and loss. The theory hypothesizes that peers are able to facilitate the adolescents' movement through the grief process or impede the adolescents' ability to work through the tasks of grief. More detailed descriptions of the relationships between the categories and sub-categories of this grounded theory will be presented next.

Core Categories

The core categories identified in this study were indicated within each interview and across all participants. In addition, they are central to the developing theory in that all other categories could be linked to them. According to Strauss and Corbin (1998), researchers often identify more than one core category, but they recommended that only one be selected and the others related to it. However, it seemed that the two core categories identified in this research were related yet still distinct from each other, and to minimize one by making it a sub-category seemed more like forcing the data. Maintaining two core categories allowed for the data to be linked together, having implications for a more general theory. As a result, the researcher identified two core categories: 'grief experience' and 'relationship dynamics'.

Grief Experience

The phrase 'grief experience' was used to describe one of the core categories that arose from the data. Participants repeatedly mentioned that the adolescents experienced a change in mood and mood-swings. As the emotional changes were examined more closely, it appeared that the youth were expressing grief reactions. As a result, the

behavioural, social, and cognitive reactions were re-examined in light of this. All participants described experiencing some characteristic(s) of the grief process. This was demonstrated through various social, emotional, cognitive and behavioural reactions of grieving. The various 'manifestations of grief' and 'manifestations of acceptance' fit with Worden's (2002, 1996) tasks of mourning. The 'grief experience' also seemed to be cyclic in nature. This was represented by the variety of 'loss experiences' and the vacillation back and forth between grief and acceptance with each loss. The commonality of 'grief experience' across participants is noteworthy, especially in understanding the psychosocial development of individuals with early-onset MS. Therefore, 'grief experience' was identified as a core category of this grounded theory.

Role of Peer Relationships

The phrase 'relationship dynamics' is used to describe the second core category that arose from the data. Once the major theme of grief was identified, the researcher asked, "What role did peer relationships play in the grief experiences of these adolescents, if at all?" It was not until this question had been asked that all the data seemed to fit into the developing theory. All participants described at least one role that peer relationships played in the psychosocial wellbeing of the youth with MS. Experiences with peers were on a continuum between positive and negative experiences and the roles covered a variety of contexts. The adolescent and the peers were forces of change on each other. Sometimes the peer relationships were impacted by the grief experiences of the adolescents with MS; however, other times these relationships shaped the grief experiences, and subsequently the adolescent with MS. This is another reason why it did not seem appropriate to identify 'relationship dynamics' as a sub-category of

grief. It was evident that peer relationships were interconnected with 'the grief experience' and not simply a resulting factor. Therefore, 'relationship dynamics' is also an important component to understanding the psychosocial development of these youth and was identified as a second core category of this grounded theory.

Sub-categories

Grief Experience

Within 'grief experience' there are three sub-categories. The first sub-category, 'loss experiences', provides a context for the grief. The other two sub-categories, 'manifestations of grief' and 'manifestations of acceptance' provide descriptions of the specific 'grief experiences' of the adolescents with MS. The following section explores each of these sub-categories in more detail.

Loss experiences. There were a number of 'loss experiences' that participants described which contributed to the 'grief experience' of the adolescents with MS. The researcher further divided these losses into two sub-categories: 'major loss' and 'secondary losses'. The 'major loss' was identified as the loss of health and was and was common across all participants. The 'secondary losses' reportedly occurred as a consequence of the 'major loss'. The 'secondary losses' which participants described were labelled as follows: 'identity shift'; 'control'; 'friends'; 'hope for future'; 'normality'; and 'assumptions about the world'. The 'identity shift' was described by participants as a change in abilities and sense of self. The term 'shift' was used to capture the process of change, as opposed to a complete loss of identity. Loss of 'control' was described by some participants as a result of unpredictable symptoms and medication use. Several participants also described the loss of 'friends' through the process of letting go

of old friendships either by the adolescent's own choice or by the leaving of friends. Other participants described a loss of 'hope for future'. This was manifested in the participants' descriptions of worry, fear of the unknown, and fear of, or thoughts of, death. A loss of 'normality' was also described by several participants. This loss captured such changes as medication, diet, ability to communicate with peers, and teenage experimentation. Finally, for some participants, loss was experienced through a challenge to the adolescents' 'assumptions about the world'. In particular, participants indicated that the assumption that the world makes sense was challenged. All participants reported an emotional, social, cognitive, or behavioural reaction to at least one of the listed 'secondary losses'. Participants' descriptions of 'secondary losses' also varied in intensity and duration, seemingly impacted by their own personal experiences and history. However, two 'secondary losses' were identified by participants, during the theory verification interview, as the most disruptive: 'identity shift' and 'hope for future'. Exemplars of the theme 'loss experiences' are included here. The first example represents the theme 'hope for future:

> It comes and goes, how I feel like sometimes I feel like I'm not worth living, and
> other times I want to live and want to go to university and all that. But then the
> thought crosses my mind, what if I can't get there? What if I'm not able to get
> there? Because of my brain and all that, I don't know.

This second example is how one parent described the adolescent's 'identity shift' following diagnosis: "Yeah, she thought she had a big red MS patch on her forehead that everyone could see by looking at her. You know, and she didn't want to bring that attention and that, and she really struggled with that." Finally, the following example

represents loss of 'friends': "And it was just it was so hard and I lost all of my friends. These people I had been friends with since like kindergarten, just were like gone."

Manifestations of grief. Participants of this study described many emotional, social, cognitive and behavioural reactions to the losses they experienced. These 'manifestations of grief' included: 'denial'; 'anger'; 'depression'; 'anxiety'; 'sadness'; 'withdrawal'; 'self-doubt'; and 'isolation'. These labels captured the most common 'manifestations of grief' but by no means cover all variations experienced by each adolescent. Most participants described experiencing some, but not all, of these reactions. They also reported varying amounts of intensity and duration of these reactions.

Denial seemed to be the most distinctive of the reactions, yet also the most difficult to identify. This reaction was usually identified by looking for what was not being said, as opposed to what was being said. Participants who demonstrated denial were unable to share many stories or descriptions of the adolescents' experiences with MS and/or their peers. The adolescents also seemed to have a lack of understanding of the disease itself. The two characteristics which seemed necessary for identifying denial were: 1) minimizing/dismissing and 2) avoiding. Participants who described experiences which were labelled as denial rarely identified any of the other 'manifestations of grief'. When one adolescent was asked about the diagnosis of MS, the responses included such comments as: "I really don't know, I don't know;" "It wasn't really anything;" and "I don't talk about it a lot. I just don't care that I have it." When describing the experiences of another adolescent, a parent responded, "Just the fact that she tries to hide it, and she tries to cover it up. Like and, you know, she doesn't want to talk about it. Just avoidance, really."

Some other exemplars of 'manifestations of grief' are included in the following. One adolescent described her anger as follows:

I hurt people's feelings a lot easier. And, more, I feel threatened in anyway, and then, yeah, I give back unpleasant responses maybe and hurt their feelings....Yeah, I get pissed a lot, a lot easier. You know, get mad from every little thing, kind of, I don't know why, but I guess just because I don't think I'm good enough."

A parent described an adolescent's isolation and sadness:

I think it was not something that she felt she could share with other people because it certainly would make her feel like she was in isolation again. But, I know that she felt, umm, I know that she was extremely upset about it. And I think maybe in a way she was second guessing that maybe this isn't such a big deal, but why do I feel this sad and if I tell anybody else then I'm just going to feel as bad.

Another parent described how an adolescent withdrew from peers, "Maybe just the lack of going out and just being around us a lot. Not necessarily clingy, but just being just with us." Lastly, the following is an example of an adolescent's emotional struggles following diagnosis: "When I do start talking about it I kind of sort of feel sad, depressed."

Manifestations of acceptance. Several participants described how the adolescent with MS experienced grief and then developed acceptance following the 'loss experiences'. Some participants who reached acceptance still described a return to the grief experience if new 'secondary losses' were experienced. Acceptance was manifested

in a variety of ways, but overall there seemed to be an integration of the disease into the adolescent's sense of self, the development of effective coping strategies, and a future-focus. Participants also described acceptance as being able to face challenges, an increase in compassion and appreciation, being able to prioritize, and having a positive perspective on life. However, not all participants described the adolescent as reaching acceptance. Whether or not an adolescent experienced acceptance of the MS did not seem to be connected to the length of time since diagnosis or severity of symptoms. Also, a couple of adolescents talked about their experiences with MS as if they accepted them, however when examined more closely and compared with parental responses it seemed the adolescents were experiencing denial instead. Two of the major characteristics which distinguish acceptance from denial were the ability to speak openly about the MS experience, and the integration of the disease into one's sense of self. One exemplar of 'manifestations of acceptance' includes the following description from an adolescent:

> I was always a caring a person, but now I'm like, I don't know, ten times more caring, like. I purposely stop to help people and open doors. Like doing just simple little things like that. So, I think it's changed me in a good way. Like it's made me a more sincere person.

Another adolescent described acceptance in this way:

> So now, it's kind of I worry when I have to, but I'm fine now, so as long as I stick to my medication, get enough sleep, and all that kind of thing, take care of myself, then I'll worry when I have to worry.

Summary of grief experience. The category of 'grief experience' can be understood as the adolescent's psychosocial experience of MS following diagnosis. The

three sub-categories provide a context for the grief and a description of that experience for the adolescents. The context for grief is comprised of a 'major loss' and a number of 'secondary losses'. How the adolescent experiences grief varies, as demonstrated in 'manifestations of grief' and manifestations of acceptance'. In addition, it seems to be cyclic in nature as the adolescents experience a number of different losses. The 'grief experience' appears to be similar to the tasks of mourning, as outlined by Worden (2002). These similarities will be discussed in the following chapter.

The purpose of this study was to explore the role of peer relationships in the psychosocial development of youth with MS. Up to this point, the grounded theory presented has focused on the psychosocial development of the youth with MS. The remainder of the grounded theory will address the role of peer relationships in that psychosocial experience; and the reciprocal relationship between peers and grief.

Relationship Dynamics

The second major theme identified in this grounded theory was labelled 'relationship dynamics'; within this theme there are six sub-categories. These sub-categories describe a variety of ways in which peer relationships are interconnected with the 'grief experience'. Sometimes peer relationships are impacted by the adolescent's grief or acceptance of the loss. However, other times the 'grief experience' shapes the peer relationships. The following section explores each of these sub-categories in more detail.

Medication-peer tug of war. The 'medication-peer tug of war' was comprised of both an internal tug of war and an external tug of war. The internal tug of war seemed to be about whether or not the adolescents with MS were going to let the medication control

certain areas of their lives. Some participants described this struggle as making a decision
between doing their injections instead of socializing with peers and socializing with peers
instead of doing injections. As one parent described it,

Cause she feels that she cannot be at 8 o'clock be, I don't know where, if she she
is not in a safe place to take her injections. And if she feels like that isn't a good
place for that, she doesn't go, or she doesn't do the injection.

This also seemed to be tied to the loss of control and normalcy. According to one
adolescent, "You don't remember what it's like to be normal. And not have to do a
needle and stuff like that."

The external tug of war seemed to influence the adolescent's struggle between
grief and acceptance. For example, some participants described the struggle between
positive and negative reactions by peers. On the one hand, the negative reactions of peers
to the injections contributed towards one's loss experience. Negative reactions included
some peers being fearful of the injections, resulting in situational isolation of the
adolescent. Participants also described the adolescent with MS being fearful of the
injections. This sometimes had a negative impact on peer relationships when the
adolescent would withdraw from peers. Alternately, positive reactions seemed to help the
adolescent with MS move towards acceptance. Positive reactions included receiving help
with injections. For example, one adolescent replied, "[my friend's], umm, learned how
to do my injections for me and stuff like that….So, yeah, he's been really great, really
great."

Shift in friendships. Following the diagnosis of MS, participants described a 'shift
in friendships'. This shift occurred in three ways, including letting go of previous

friendships, deepening of old relationships, and the development of new friendships. The change in relationships with peers seemed to be connected to the grief process in a number of ways. First, the letting go of old friends connected with the 'secondary losses' the adolescents with MS experienced. In some cases, the adolescents' friends backed off or left the relationship, contributing to the 'grief experience' of the adolescent. This was often manifested in depression, withdrawal, and sadness. In other cases, the adolescents backed off or left relationships with peers because of their own emotional struggles, in particular those which were 'manifestations of grief'. For example, one adolescent described it as follows:

> I'm not quite as sociable anymore. I I can't do everything that others do. Yeah, so I don't go out with them all the time where they're going or doing the things that they're doing....I'm I just say I'm I'm more, I keep more to myself....Like I'm darker inside, so to say.

According to some participants, the loss of social support from peers added to the negative emotional and behavioural reactions of the adolescents. For others, however, it helped them to develop acceptance of their disease, as one participant described, "For me to hang onto negative friends and stuff like that, like my circle of friends have changed, I don't tend to try and hang onto people anymore."

The second component to 'shift in friendships' was the deepening of old relationships. These relationships were sometimes already close friendships which grew closer, yet others were acquaintances who moved to the position of close friends. This deepening of friendships was a result of two major factors. The first factor was positive reactions from peers, represented by support, trust, and active involvement in the

wellbeing of the adolescent. The second factor was the process of relationship testing and disease information sharing by the adolescent with MS. One exemplar of the deepening of old relationships includes: "It actually brought me much closer to my friends, to know that they wouldn't leave me. Like with all the stuff happening with me falling down the stairs and everything." Another parent participant described it like this:

> She actually became more supportive....Well, like she's like at our house all the time, we're just more close to each other. And she helps me out at school all the time, and when I'm sick she gets me Tylenol and brings me water and all that stuff.

The third component to 'shift in friendships' was the development of new friendships. Some participants described this as a means of self-preservation for the adolescent with MS. That is, it was a way to escape the unhealthy relationships which were only adding to the grief and not facilitating the shift to acceptance. For example, one parent described it this way:

> I'd like to say, that a better choice of friends. You know that finding out who you're more comfortable with and maybe she doesn't tell people, oh I'm sure she doesn't tell people initially. And, maybe for her it's self preservation. If they have a negative reaction, then maybe she doesn't want to deal with that, you know.

Others described the development of new relationships as an opportunity for a new beginning. This new beginning was the start to a life where MS was just another piece that made up who the adolescent was. It also facilitated the adolescent's movement towards acceptance of the disease. One adolescent described the benefits of new friendships in the following: "Umm, a couple of the close friends I have now I met after

being diagnosed and I met them telling them this is what I have going on. And they were welcoming me with opening arms and stuff."

Supportive relationships. All participants described the adolescents with MS as having at least one close, supportive friend. Most participants also described the transition from a large group of peers to a smaller group of reliable and supportive close friends in the first couple of years following diagnosis. These peers played a role in the 'grief experience' by providing 'supportive relationships'. 'Supportive relationships' seemed quite important in helping the adolescent move towards developing acceptance of their disability. In particular, the active involvement of close friends was essential in this process. Active involvement was described as helping with medication, taking notes in class, learning about MS on their own, and assistance with mobility. Hands on assistance was described by one adolescent in this way:

> Just like, carrying me and. [My friend] used to always give me piggybacks wherever I wanted to go or she'd carry me cause she's kind of bigger. They carry my shoes if I need them to. [My friend] pulled me around in a wagon for a little while. Yeah, I don't know, they help me a lot.

Another adolescent described the active involvement of friends in this way:

> Once they found out they did their own research to try and figure out exactly what was going on. Cause like I could tell them the basics and things like that but they actually you know researched over the Internet and got pamphlets and all that kind of stuff....So that's been really awesome. To have them like having to get to know what's wrong with me and then not just going on the basis of what I say.

Other characteristics of 'supportive relationships' included unconditional acceptance, mutual understanding, listening, and empathy. The value of shared understanding was demonstrated in this adolescent's description: "With my friend, because her mom has MS....Well, because then she actually knows what I have, and she knows what it is like, because of her mom." In general, the support received from peers was ongoing and usually of a casual nature. In addition, acquaintances sometimes played an important role in helping the adolescent move towards the acceptance stage by providing an escape from the MS and an opportunity to maintain normalcy.

However, participants also described times when the 'supportive relationships' became too intense. There seemed to be a line that peers could cross, where they became over-protective and expressed excess worry. This over-protection and emotional expression challenged the adolescents' ability to cope with their own grief and loss. One adolescent described the experience this way: "Yeah, sometimes they try and watch out for you a little too much. You're like 'hey, we're going out, having fun, don't babysit!'...And it's horrible, because you have this huge amount of guilt."

Dealing with others' worry. Another component to 'relationship dynamics' became apparent in the adolescent's need to cope with the worry of others. Specifically, 'dealing with others' worry' seemed to be tied in with the idea of overprotection mentioned in the previous sub-category. When peers knew of the MS and responded in an overprotective manner, it seemed to contribute negatively towards the adolescent's psychosocial wellbeing. In particular, one participant suggested that it prolonged her grief experience. As a result, some adolescents kept their MS a secret so that they could cope better.

So having people worrying about me all the time and wondering if you know, oh

my gosh, is she going to be okay tomorrow and how are you feeling today and

you know, how are you dealing, how are you coping? It just made me feel like I

had to worry about something.

Other participants described friends as being an important support system in order to

escape parental concern.

I feel like I don't want to talk to [my parents] about things when I'm having a

problem. I know she would understand, she'd totally be there to help me. But I'd

feel bad if I talked to her about it because she worries, and I don't want that stress

upon her. I'd rather just keep it to myself, or talk to a friend about it or whatever,

but, a lot of the times I don't like to tell my mom because I don't want her to

worry.

Talking about MS. How adolescents talked about their MS to their peers also

seemed to impact their experience of the grief process. Initially, the adolescents were

guarded about revealing their diagnosis to others. This seemed to be a result of the

adolescents' 'grief experiences'. For example, one adolescent feared the potential threat

to identity: "And I don't know, I just don't like telling guys, I don't know what they're

going to say. They'd probably be like oh my girlfriend's a gimp or something. Or she has

a disease or something like that."

For another adolescent, it was her uncertainty about the future that kept her from sharing

her diagnosis with friends. Still other participants described withholding the diagnosis as

a way to avoid attention, sympathy, and excess worry, which only added to the 'grief

experience'. However, talking about the MS was also described as an important

component in the transition towards acceptance. Reportedly, the adolescents were more willing to discuss their diagnosis once they had had a chance to process the associated losses. They also needed time to gather evidence that others would not reject or isolate them. The support they received after revealing their diagnosis facilitated the move towards acceptance. In addition, it helped to bolster the adolescents' self-esteem because they became an expert on the disease.

> Umm, I think it's made it easier for me to deal with, just cause the more questions people ask the more I like to know. So then I go and do my own research, and I go read books, read magazines.

In general, though, it was only close friends and a few acquaintances that were told about the MS.

Acting as if. The final sub-category of the 'relationship dynamics' that arose out of the data in this study was labelled 'acting as if'. Specifically, it refers to the behaviours and cognitions used by the adolescents to hide their MS. Some participants described the adolescents hiding their diagnosis from their peers, especially acquaintances or general peers, in order avoid negative reactions.

> Yeah, like those are the ones that I just see casually on the streets or whatever and they ask me and I'd be like, cause I was tripping and falling everywhere, and I wasn't sure how those people would react to it, so I just told them I broke my leg.

In this sense, the disease did not become a factor within the relationship, which seemed to help the adolescent cope with the diagnosis. Other participants described the adolescents hiding their MS as a way to maintain some sense of normalcy after diagnosis.

> Umm, and I've kind of chosen not to tell a lot of people just because I don't want
> things to change. Umm, I don't want to be treated differently....It's kind of like
> an escape to go out and hang out with them and not have to deal with anything, or
> worry about anything, or think about anything.

Still other participants described how the adolescent would act as if the disease was not there at all. This seemed to be a manifestation of denial. A parent described this style of 'acting as if' in the following way:

> Like she'd have to have this [IV catheter] in her arm for the night, actually for
> three nights. She actually went to a party with that. And, and I knew what she was
> thinking, so I went and bought her a sweat band, okay. So I said, "You can go out
> and put this around and you can cover it." And so she did.

Summary of the role of peer relationships. Peer relationships are interrelated with the grief process experienced by the adolescents with MS. Sometimes the 'grief experience' can shape the development of those peer relationships. However, peer relationships can also impact how the adolescents experience grief. Some of the contexts in which this took place included medication, supportive relationships, changes in friendships, coping with worry from others, talking about MS, and acting as if.

Summary of Grounded Theory

The grounded theory generated in this study is summarized in two core categories. The two core categories are 'grief experience' and 'relationship dynamics'. All participants identified some type of 'grief experience' for the adolescents with MS. Identifying the presence of grief was essential in understanding the psychosocial wellbeing of these adolescents. Participants also described a number of ways in which

peer relationships were interconnected with the 'grief experience'. The 'relationship dynamics' and the 'grief experience' were linked in a reciprocal manner. Specifically, they each had an impact on how the other was experienced. For this reason, both are identified as core categories.

Each of the core categories is comprised of several sub-categories which provide more detail and meaning to the grounded theory. The sub-categories of 'grief experience' include: 'loss experiences'; 'manifestations of grief'; and 'manifestations of acceptance'. Each of these contributes to a framework of the grief experienced by the adolescents with MS. The sub-categories of 'relationship dynamics' include: 'medication-peer tug of war'; 'shift in friendships'; 'supportive relationships'; 'dealing with others' worry'; 'talking about MS'; and 'acting as it'. Under each of these sub-categories, descriptions are provided as to how peer relationships play out in connection with the grief process. Collectively, the categories and sub-categories of this grounded theory provide a comprehensive description of the roles grief and peer relationships play in the psychosocial development of adolescents with early-onset MS.

<div align="center">Research Process Variables</div>

Several variables may have had an impact on the results of this study. First of all, the researcher's personal experience with the subject area had an influence on several areas of the research project. Second, the source of data (i.e., adolescents, parents) seemed to impact the detail provided on various interview questions. Third, language barriers may have limited the data collection process with some participants. The researcher's perspective on how these variables influenced the research process and data obtained is explored in the following.

Researcher Self-Disclosure

As previously mentioned, theoretical sensitivity is an important technique used in grounded theory. Theoretical sensitivity is the attribute of having insight into the data and being able to give it meaning. Corbin and Strauss (1998) identified personal experience as one source for increasing the researcher's sensitivity to the data. It was the researcher's own experience with being diagnosed with MS during late childhood that contributed to the development of this study. However the researcher must also be cautious in the use of personal experience so as not to unduly influence the data collection process or stray away from the data during analysis. As personal experience was a source of theoretical sensitivity for this researcher, steps were put into place so as to use this experience correctly.

The first use of personal experience was in the development of interview questions. The researcher's personal experience assisted in the development of the research questions. Specifically, it helped to identify issues relevant to this population. The first step put into place to ensure correct use of theoretical sensitivity was through the use of open-ended questions. This was critical so that participants had the opportunity to share their stories without being influenced by the researcher's personal experience. Second, the interview questions were distributed to the thesis supervisor, committee members and colleagues to assess the generality and applicability of the questions to the study. Pilot interviews were also completed in order to assess if the questions were providing an opportunity for uncovering relevant information without leading the participant. The researcher's personal experience seemed to come into play most when asking participants for expansion or clarification of their responses. Specifically, it

provided a comparative base for asking questions about MS experiences. This seemed to be useful in building a trusting relationship between the participants and researcher so that the participants could openly share their stories. The researcher also employed a strategy recommended by Strauss and Corbin (1998) by looking for opposites. For example, personal experience may have influenced the researcher to ask a more specific question about negative experiences with peer relationships. Then, using the strategy discussed by Strauss and Corbin, the researcher also inquired about positive experiences with peer relationships. This strategy was effective in getting more detailed descriptions from participants without being overly influenced by the researcher.

Personal experience also may have impacted the data collection process. Specifically, the researcher self-disclosed her personal experience to participants. The purpose of this was to be open with participants so that they were aware of the experience and knowledge the researcher had on the topic. This approach was also useful in the development of a trusting relationship between researcher and participants. This relationship seemed important in aiding participants in disclosing their own story. The researcher self-disclosed to the adolescents prior to each interview in hopes of increasing the participants' comfort with sharing their own story. Initially, the researcher disclosed to parents at the end of the interview. This decision was made so as to avoid influencing the parental responses. However, the parents seemed to want to share more of their story after the researcher self-disclosed, so the decision was then made to disclose to parents at the beginning of the interview. This seemed to be more effective during the interview process and did not seem to bias the data in any way.

Personal experience may have influenced the data analysis process. Specifically, the researcher's personal experience may have proved useful by making the researcher more sensitive to certain elements of the data that another researcher may not have picked up on. To manage this, though, a dedicated use of constant comparison analysis was important. The researcher was initially quite cautious with analysis, being aware of the potential for reading too much into the data. As such, the use of constant comparison analysis was a very useful tool for limiting the opportunity for drifting away from the data. The researcher also checked in with the thesis supervisor during the analysis process and developing theory in order to obtain some neutrality. When it comes to using sources of theoretical sensitivity, the process the researcher ultimately needs to keep in mind is maintaining a balance between objectivity and sensitivity (Strauss & Corbin, 1998).

Sources of Data

Both adolescent and parent perspectives were used as sources of data. Previous research has identified these as useful sources for identifying the experiences of children and adolescents with chronic illness (e.g., Adams et al., 2002). In fact, Adams, Streisand, Zawacki, and Joseph (2002), reported that parents were more likely to identify illness-related social problems than the children and adolescents. For the present study, it was anticipated that parents would provide a different and valuable perspective on the adolescent's peer experiences and social behaviours. Their perspectives were expected to be most helpful in identifying the social behaviours of the adolescents with MS.

The parents in the present study varied in their ability to share information about their child's peer experiences and social behaviours. Parents seemed best able to provide detailed descriptions of their observations of and experiences with their adolescents'

social behaviours. However, in regards to their adolescents' experiences with peers, many parents demonstrated a limited awareness. For example, when asked about the adolescent's experiences with general peers, one parent responded:

> Once she started high school, and there was basketball, her and I didn't see a whole lot of each other. Cause I did 10 hour days at work, and then she would have basketball til 5:30. So I would get off work, pick her up, she was home, inhaled supper and was gone. And so if there was something really irritating, I would have to pick a fight to get her to yell and scream at me to find out any information.

When asked about the adolescent's experiences with acquaintances, another parent responded, "I didn't talk to those people. Like what their opinion in this is (....) I don't know, I really don't know." In spite of some parents not being able to share detailed descriptions of their child's peer experiences, others proved to be very useful sources of data for this information.

There was a definite discrepancy between the study done by Adams, Streisand, Zawacki, and Joseph (2002) and the present study regarding the usefulness of parent perspectives. Upon closer analysis, it was identified that the referenced study was quantitative in nature. As such, parents were not required to provide detailed descriptions of their children's relationships with peers; instead they provided responses to short, brief statements. The implications of the source of data will be discussed in Chapter Six.

Language Barrier

The final variable which may have impacted the data collected was a language barrier. Several participants were immigrants to Canada and their grasp of the English

language varied. The researcher chose to include them as participants in order to obtain their unique perspectives. Some of these participants were able to share their stories with detailed description. However, in one case, the adolescent was required to translate for the parent. In this case, it can not be guaranteed that the translation was accurate. Sometimes it seemed as if the adolescent was filling in extra detail. In addition, the parent may not have felt comfortable sharing information with the adolescent present. The parent also reported having very limited interaction with the adolescent's peers because of the language barrier. In spite of these limitations, meaningful data was still obtained by the researcher. Even though this communication challenge likely impacted the data collected from this interview, it is not expected that it drastically impacted the results of this study. This was the final interview completed and data saturation was already nearly obtained.

Summary of Research Process Variables

Research process variables inevitably shape the data collection and analysis process. The researcher took precautions to control for anticipated variables. However, it was not possible to control for the unexpected variables of data source and language barrier. The implications of these variables on the study and on future research will be · discussed in Chapter Six.

Conclusion

The results of this study help to provide an understanding of the role peer relationships have in the psychosocial wellbeing of adolescents with MS. Psychosocial wellbeing is represented through the grief experience of these adolescents. Several general conclusions can be drawn from the data provided by participants and the

subsequent grounded theory. First, adolescents diagnosed with early-onset MS experience grief in reaction to the loss of health. This grief reaction also has implications for their social skills. Second, numerous other losses occur in conjunction with diagnosis, each carrying potential consequences for psychosocial development. Third, peer relationships can play important roles in the grief experiences of adolescents with MS. Sometimes these roles may be facilitative to the grief process; other times they may be detrimental to the adolescent experiencing grief. Fourth, the quality of peer relationships (e.g., close friends versus general peers) seems to impact the nature of experiences with those peers. The implications of these conclusions for counsellors and health-care professionals, and future research will be discussed in Chapter Six.

CHAPTER 5: DISCUSSION

The purpose of this study was to explore the psychosocial experiences of youth with multiple sclerosis. In particular, a focus was placed on the role of peer relationships and social behaviours on those experiences. Grounded theory was used to develop a theoretical model which portrayed these experiences. There were two primary conclusions drawn from the theory. The first reflected the significance of grief in understanding psychosocial development in adolescents with MS. The second identified that peer relationships play a variety of roles in this grief process. Together, these two conclusions create the core of the grounded theory created out of the data in this research.

The purpose of this chapter is to discuss the contributions these research results make to the literature. First, a summary of the themes presented in the primary literature review is presented. This is followed by a discussion of the conclusions drawn from the grounded theory in relation to the relevant theoretical and empirical literature. In addition, as previously stated, grief was identified as a central theme to the grounded theory. Therefore it is necessary to identify the contributions of this study to the grief literature, which is also explored within this chapter. Overall, this study reinforces and expands on many themes present in the literature and provides a unique understanding of the psychosocial experiences of youth with early-onset MS.

Peer Relationships and Psychosocial Development

The initial premise for this research was that peer relationships create an important context for psychosocial development in children and adolescents. As such, the primary literature review examined the literature which addressed this issue. A particular focus was placed on how this social context can impact the development of children and

adolescents with chronic illness. The rest of this chapter will focus on the contributions of this study to the research on psychosocial development in children and adolescents with chronic illness.

Summary of Thematic Review of Literature

The primary literature review for this study was presented in Chapter Two. This literature review presented an overview of multiple sclerosis, roles for counsellors in the treatment of children and adolescents with the disease, and a review of the literature addressing the role of the peer group and the individual's social skills in the psychosocial development of children and adolescents with chronic illness. Initially, a need was identified to address the psychosocial development of youth with MS. In light of the developmental tasks of children and adolescents, a focus was placed on peer relationships. The role of peer relationships was determined to be influenced by the quality of the relationships. The literature review also identified three primary factors which impacted the study of peer relationships and chronic illness: the operationalization of peer group (e.g., close friends vs. general peers); degree of disability experienced by the individual with the disease; and school absence and the school culture. In regards to social skills, the literature suggested that negative social behaviours can interact with the stigma of a chronic illness to further impact the social experiences of individuals with the illness. In general, the literature suggested that peer relationships have the potential to influence psychosocial development, however it is also necessary to consider the intervening variable of social skills.

Identification of limitations and gaps in previous research was also presented in the primary literature review. One of the primary limitations was a result of the

methodology used by previous researchers. Specifically, there was a lack of research which tapped directly into the adolescents' perceptions of their experiences with chronic illness and peers. Also, the peer group was operationalized in a variety of ways, making it difficult to draw more general conclusions on the role of peer relationships. The adolescents' perceptions about their own degree of disability were also overlooked by previous research. Finally, the most notable gap in the literature was the paucity of research addressing the psychosocial development of children and adolescents with MS.

To facilitate the discussion around the contributions of this study to the literature a brief review of the conclusions drawn from the grounded theory will be reviewed. First, adolescents diagnosed with early-onset MS experience grief in reaction to the loss of health. Grief seems to be an expression of psychosocial wellbeing in these individuals. This grief reaction also has implications for their social skills. Second, manifestations of grief, resulting from numerous secondary losses, occur in relation to the loss of health, each carrying potential consequences for psychosocial development. Third, peer relationships can both facilitate and hinder the grief experiences of adolescents with MS. Fourth, the quality of peer relationships (e.g., close friends versus general peers) seems to impact the nature of experiences with those peers. The following section will discuss how these conclusions contribute to and expand on the literature presented in the primary literature review.

Contributions to Psychosocial Development and Chronic Illness Literature

In general, the main conclusions drawn from this study support most of the existing literature concerning the themes presented in the primary literature review. First, the identification of loss and grief experiences emphasizes the importance of addressing

the psychosocial development of youth with MS. It also supports the argument for a more general operationalization of psychosocial development. Second, the role of peer relationships in the grief experience suggests that peers are important to psychosocial development, especially within the context of chronic illness. Third, the quality of peer interactions was found to influence the role they played. Finally, the three factors identified in the literature to impact peer relationships were only partially supported. Specifically, the importance of how one operationalizes peer relationships was supported. The second two factors represented in the data, though, were less noteworthy. Descriptions follow of how the findings of this study do or do not support each of these themes in the existing literature.

Psychosocial Development in Chronic Illness

The findings of this grounded theory support the existing literature which suggested that chronic illness impacts psychosocial development. Previous research has operationalized psychosocial development in many specific ways (e.g., Adams, et al., 2002; Boekaerts & Röder, 1999; Meijer, et al., 2000). Consequently, researchers have not been in agreement about the impact of chronic illness on psychosocial development. However this study operationalized this impact in the more general terms of social, emotional, and behavioural wellbeing. The concept of the grief experience identified in this study seems to capture each of these domains. In addition, the concept of grief accounts for the numerous ways in which previous researchers have operationalized psychosocial development. For example, self-esteem, behavioural and emotional problems, social adjustment, peer relationships, anxiety, depression, aggression, and social withdrawal have all been used to define psychosocial development (Boekaerts &

Röder, 1999; Brown & Macias, 2001; Wallander & Robinson, 1999). Each of these descriptions can be accounted for within the grief experience model identified in the grounded theory developed from this study. Thus, the argument that chronic illness impacts psychosocial development is supported.

The Role of Peers in Psychosocial Development

The findings from this study indicated support for the importance of peer relationships in the psychosocial development of children and adolescents with chronic illness. Specifically, this research validated the need to consider the quality of the interactions between adolescents with chronic illness and their peers. Bukowski, Newcomb, and Hartup (1996), argued that positive friendships promote development and adaptation. This was demonstrated in the grounded theory through the subcategories of 'supportive relationships', 'medication-peer tug of war', and 'talking about MS'. For example, one participant described the importance of being able to talk about her MS with her friends in building confidence and self-esteem.

> And it's kind of, if they're willing to learn, it puts a smile on my face, it makes
>
> me feel kind of better about it because then I can actually answer the questions
>
> and then they know more and I know more as well. And I kind of know more
>
> about how people react and they know more about what I'm going through and
>
> what's going on with me. So, umm, I mean I really like that.

Positive experiences with peers seem to ease the grief experience and promote acceptance of the illness. This further seems to facilitate the developmental tasks of these adolescents, including identity development and a sense of belonging. In contrast, researchers have suggested that negative peer relationships can have an unhealthy impact

on psychosocial development (Shiu, 2001; Sullivan, 1953, as cited in Rubin et al., 1998). Children and adolescents with chronic illness were reported to be at greater risk for these negative relationships (Kef, et al., 2000; La Greca, 1990). The results from this study confirm that adolescents with a chronic illness like MS do experience negative peer relationships. These unhealthy peer interactions were also demonstrated to have a negative impact on the adolescents' psychosocial development via their grief experiences. This was especially apparent in the sub-categories of 'medication-peer tug of war', 'shift in friendships', 'dealing with others' worry', and 'talking about MS'. In addition, it was represented within 'secondary losses' through the loss of friends. For example, one adolescent expressed feeling sad and out of control following the loss of friendships. "It was really hard. It was really really hard. I cried a lot because of it, because there wasn't really anything I could do....I wasn't trying to be sick. It was, I mean it wasn't in my control." It was apparent from the results of this study that the quality of experiences with peers plays an important role in the psychosocial development of adolescents with MS.

Factors Impacting Peer Relationships in Chronic Illness

In the primary review of the literature, three factors were identified to impact the quality of peer relationships. The results from this study provided evidence suggesting that the quality of experiences with peers was influenced by the level of intimacy within the peer group. As in previous studies, the research demonstrated that adolescents with chronic illness, like MS, do have a group of supportive, close friends. One adolescent described it this way, "...I have my close little circle of friends and umm it makes it a lot easier because I know I can go to them and talk to them about it." Previous research has

also suggested that adolescents with chronic illness had a smaller network of friends than their healthy peers (Kef, et al., 2000). Similarly, participants in this study described a decrease in their number of friends. As one parent described, "She's taken some friends that aren't so good for her and she's replaced them with a more select crowd of good friends." This was accounted for in the sub-category of 'shift in friendships'. Participants explained how they tested relationships and developed deeper connections with peers who were supportive and chose to leave relationships which were not supportive. In terms of acquaintances and general peers, different experiences were described than with close friends. The adolescents in this study generally kept emotional distance from these individuals. This was usually out of fear of potential reactions by peers. According to one adolescent, "...these people really do not know about me having MS and I'm not eager to tell them either. Because it's none of their business, you know." Unlike previous studies, the results in this research did not generally find adolescents with MS to be bullied, teased, or isolated by the larger peer group. However, this may have been a factor of these peers being unaware of the disease. Nonetheless, support for diverse experiences between close friends, acquaintances, and general peers was found.

The second factor identified by previous research to have an impact on the quality of peer relationships was degree of disability. This factor was not found to be prominent in the current research findings. Previous research on MS in adulthood suggested that individuals who experienced disability were more likely to withdraw from peer relationships (Hakim et al., 2000). Degree of disability was not found to be a reason for withdrawal from social interactions among the participants of this study. Research on other childhood chronic illnesses also suggested that degree of disability was a factor in

quality of peer relationships. Thies (1999) suggested that the prolonged symptoms of chronic illness decreased energy, making it difficult for youth to participate fully in the social and academic life of the school. The findings in this grounded theory support this statement; however participants reported that it was not the quality of the relationships that was impacted, but merely the frequency of the interactions. One adolescent described it in this way, "Like the relationships themselves really haven't changed. Like we're still good friends and stuff, but like what we do and how often we really talk kind of has changed." In addition, previous research (Sexon and Madan-Swain, 1993) described how the negative impact of disability on body image presents a challenge to adolescent self-esteem. None of the participants in this study identified body image as a concern. Rather, the challenge to self-esteem was described as coming more from the stigma of chronic illness. Finally, peers' perceptions of an individual with a chronic illness were also suggested to be impacted by the severity of disability. Cadman, Boyle, Szatmari, and Offord (1987) found that isolation was much more prevalent among children with chronic illness and disability than children with chronic illness but no disability. Once again, based on the adolescents' perceived degree of disability, this did not seem to be present in the data found in this research. Overall, the results of this study did not support the premise that degree of disability from MS influences the nature of peer relationships.

Cultural milieu and school interruptions were identified as the third factor to influence the quality of peer relationships. According to Shiu (2001), frequent and/or extended absences from school disrupt friendship formations and can interrupt friendships. Participants in this study did not report school absence to negatively impact

the quality of the adolescents' peer relationships. In fact, one adolescent described the opposite:

> ...we had professional development days, I missed some of those, and like when
>
> we went back to school I didn't go for like a week, so I think I just went for one
>
> or two days, so, it didn't really make a difference. But [my friends] help.

However, most participants did not mention that the adolescents with MS missed any significant amount of school. For this reason, it is difficult to conclude what the impact of MS would be on the experience of school milieu for individuals who were absent for any significant amount of time. Other research has also found that school absences can have a negative impact on the psychosocial development of children and adolescents with chronic illness (see review of literature in Sexon & Madan-Swain, 1993). Several adolescents with MS in this study described the challenge of missing school and how it negatively impacted their self-esteem and identity development.

> I couldn't say it made me stronger, because it didn't. It kind of put me down more
>
> because I'm always thinking what if I can't do this, what if my brain can't take it?
>
> You know, like it will over accumulate. As it happens sometimes at school with
>
> all the information, and all that.

Therefore, school interruptions may not have a direct impact on the quality of peer relationships. However, they do seem to have a bearing on the psychosocial development of these adolescents.

Social Skills as a Variable in Peer Relationships

Previous research has suggested that children and adolescents with chronic illness are more likely to demonstrate ineffective social behaviours than their healthy peers (e.g.,

Cadman, et al., 1987; Kliewer, 1997; Phipps & Steele, 2002; Thies, 1999). These maladaptive behaviours are suggested to have a negative impact on the development of healthy peer relationships. Some of the behaviours identified included lack of social participation and more submissive social behaviours (Cadman, et al., 1987; Kliewer, 1997; Meijer et al., 2000). These findings are supported by the results of this study. However, the results of this grounded theory would suggest that these negative social behaviours are actually manifestations of grief. For example, participants described the adolescents withdrawing from friends because of their own lack of hope for the future, lack of control, and fear of the unknown. One parent described an adolescent's initial withdrawal and then acceptance of the disease in this way: "I think she did that herself. I don't, don't think, that it that it right now impacts at all. Umm, and I think that that's probably a consequence of her becoming more used to it." Other participants described going along with what peers were doing so that they could maintain normalcy. Consequently, social skills, as manifested through the grief experience of the adolescent, can have a negative impact on the development and maintenance of peer relationships.

Enhancements to Existing Psychosocial Literature

The main conclusions identified in this grounded theory enhance the existing psychosocial literature by addressing some of the limitations and gaps in the literature. First of all, the concept of grief offers an explanation for the mixed results found in the psychosocial development literature. Second, this research identifies the need for operationalizing the peer group; that is, there is a necessity for having clarity about who belongs to the peer group and distinguishing between the different levels of closeness. Third, the use of grounded theory addresses previous methodological limitations. Finally,

this study provides one of the first intensive looks into the impact of early-onset MS on

psychosocial development. The results of this study supplement the existing research in

many important ways.

Grief as a Model for Psychosocial Development

The primary review of literature determined that there were mixed findings in

regards to psychosocial development within chronic illness. Boekaerts and Röder (1999)

argued that the mixed findings were a result of the different illnesses being studied and

individual variation. The presence of a grief experience may provide an alternate

explanation. For example, the variation in findings may be accounted for by the

individual response to the grief process. Individuals who are working through the pain of

loss are more likely to demonstrate reactions such as withdrawal, sadness, and anxiety,

whereas those who are completing the task of letting go of the loss are more likely to

express acceptance, and other positive, future-focused reactions. The adolescents with

MS in this study did not all demonstrate the exact same struggles in psychosocial

development at the same time. However, when the larger picture was examined, it was

possible to identify some experience of grief for each of the adolescent participants. The

concept of grief naturally takes into account individual variation in that no two

individuals experience grief in the exact same way, at the exact same time. However, this

does not negate the fact that there are definitely common manifestations of the grief

experience. As such, it seems as though the concept of grief offers a framework for

understanding psychosocial development in children and adolescents with chronic illness.

Operationalizing the Peer Group

Previous research has not generally addressed variation in the quality of peer

relationships based on how close individuals are to their peers. In fact, it was quite

common for peers to be operationalized simply as close friends (e.g., Kef, et al., 2000;

Reiter-Purtill, et al., 2003). However, the problem with this limited view on peer

relationships is that it does not account for different experiences which might occur with

less intimate peers like acquaintances or general peers. The results of this study

demonstrated that the quality of these relationships is tangibly different than close

friends. For example, close friends were described as contributing support, whereas

general peers were not. In addition, when researchers do not distinguish between these

different types of peer groups, they cannot identify the roles these latter two groups play

in development. Participants in this study described how acquaintances facilitated the

grief experience by providing an escape from the adolescents' emotional turmoil. In

contrast, general peers were identified to almost never be involved in the grief process. In

fact, very rarely did these peers even know about the adolescent's disease. By delineating

between close friends, acquaintances, and general peers, this study was able to obtain a

clearer understanding of the role of peer relationships in psychosocial development for   ·

adolescents with MS.

Methodological Limitations

Most of the research presented in the primary literature review utilized

quantitative methodologies. Specifically, surveys seemed to be the most common data

collection tool (e.g., Kalb et al., 1999; Madsen, Roisman, & Collins, 2002). However, it

was determined that these measures were insufficient for measuring the unique

experiences of individuals with chronic illness, including their social functioning. It was argued that identifying adolescents' perceptions about their experiences was important in understanding psychosocial wellbeing. For this reason, qualitative methodology, specifically grounded theory, was chosen for this study as a way to tap into these perceptions. The rich descriptions received from participants support the value of using this type of approach to understand the adolescents' perceptions of their illness and its consequences. Grounded theory was also developed to explore social and social psychological processes. This approach was demonstrated to be effective in understanding the processes taking place between adolescents with MS and their peers. Consequently, by using grounded theory, this study provides a unique, descriptive view into the experiences of adolescents with MS and their peer relationships.

Psychosocial Development in Early-Onset MS

After reviewing existing literature, it became clear that the experiences of children and adolescents with MS are mostly unknown. The research that is available has mainly focused on diagnostic and medical treatment issues. It became clear that there was a need to gain a deeper understanding of the actual experiences of these individuals who must live with the disease. As this area was virtually unexplored, the researcher chose to use grounded theory. The benefit of using grounded theory was that it created an opportunity to begin developing theoretical hypotheses about the social and social psychological processes taking place for these individuals. Consequently, the results of this study offer the first theoretical framework for understanding psychosocial development in adolescents with early-onset MS. This grounded theory has contributed to the study of this area in many ways. First, it has created the opportunity for increased understanding

of the experiences of individuals with early-onset MS. Second, it has the potential for guiding future research in this area. Finally, the theoretical framework can be used to guide the development of counselling programs, interventions, and services for children and adolescents with early-onset MS. The first of these contributions has been addressed in this chapter; the latter two will be elaborated on in Chapter Six.

As described above, the results of this study both support and supplement the existing literature on psychosocial development, peer relationships, and chronic illness. Support was found for addressing psychosocial development, the role of peer relationships, differing experiences due to peer group system, and social skills as an intervening variable. Additionally, this study enhances current literature by addressing previous limitations and filling in gaps where research was lacking. Most importantly, it offers the first theory for understanding the psychosocial wellbeing of adolescents with MS, and the role of peer relationships in that process.

Contributions to Grief Literature

The secondary literature review uncovered the progression of grief research during the last four decades and demonstrated the expansion of grief literature to individuals with chronic illness. First of all, there does seem to be similarity in the general tasks that one goes through in the grief process and how they may be manifested. It is particularly important to note, however, that every individual has a unique experience of grief in terms of sequence of events, duration, and intensity. Further, this experience can be impacted by level of development and the type of loss experienced. Many of the issues presented in the grief literature are consistent with the themes that arose in the 'grief experience' identified in this study.

The grounded theory developed through this research corroborates and enhances the current grief literature. First of all, Worden's (1996, 2002) four tasks of mourning were supported by the 'grief experience' identified in the grounded theory of this study. In addition, the impact of grief on developmental tasks was also supported through participants' descriptions. Peer involvement in the grief experience was another theme identified which substantiates current literature. Finally, the ambiguous and cyclic nature of grief in chronic illness was also delineated within this research. Each of these themes from the grief literature is further explored in the following. Where appropriate, participant responses are used to augment the discussion.

Tasks of Mourning

The four tasks of mourning identified by Worden (1996, 2002) are represented in the current study through the sub-categories 'manifestations of grief' and 'manifestations of acceptance'. This model was originally developed to describe the grief process of individuals who were experiencing death and dying. The grounded theory developed in this study expands on this by demonstrating that adolescents with MS also experience a similar grief process. As grief was not the intended focus of this study, the unfolding of the grief process was not explored in detail. However, upon close examination of the 'grief experience' all four tasks of mourning that Worden identified were present in the data. This suggests that despite the type of loss, these four tasks may be universal to the grief process.

One of the tasks Worden (1996, 2002) identified was acceptance of the reality of the loss; a person who did not complete this task was said to be in denial. Conversely, someone who completed this task recognized the actuality of the loss. Denial of the loss

of health of the adolescent with MS was described by several participants in this study. According to Worden (2002), denial usually involved the facts of the loss, the meaning of the loss, or the irreversibility of the loss. In concordance with this, participants described denial of the loss as: 1) lack of concern for the impact it was having, minimizing or denying symptoms and the possibility of flare-ups; 2) detachment from the disease, minimizing it's presence in their lives; and 3) avoidance of anything disease related, including learning about the disease. One adolescent's parent described avoidance as follows:

> Like we have talked a few times, you know if there was a teleconference or something, is there anything you would want to listen in on? Not a chance. Or reading material would come and he doesn't look at it. The only time he looked at it was when there was an article about marijuana on the front page cover and that caught his eye. So he read that one, that was it. Like, it was just, I don't know if it's just because he feels he needs to know as much as he needs, and enough is enough, or if it's a denial thing.

Another adolescent described her denial in this way:

> I didn't want anybody to notice when I was shaking, I didn't want anybody to see if I stumbled or. I was trying to hide it so bad. Yeah, and I kind of thought if I didn't admit that I had it, it wasn't kind of there kind of.

It is important to clarify, however, that denial can take on both healthy and unhealthy forms (Kahn, 1995). The previous examples demonstrated unhealthy denial in that they prevent the individual from moving on towards full acceptance of the loss. However, healthy denial can be important in maintaining the individual's hope for a relatively

normal life. This was represented in this study through the sub-category 'acting as if'. Sometimes it was necessary for the adolescents to pretend the MS was not present in order to fully participate in their relationships with their friends. In addition, it provided a moment of reprieve from the challenges of living with a chronic illness. Other participants described what it was like to experience acceptance of the reality of their loss of health. Consistent with the literature, these individuals were able to identify the presence of MS in their lives on both an intellectual and an emotional level. This acceptance, however, does not mean that the individual is okay with the loss; in fact, one is more likely to express an emotional reaction to the loss. For example, one adolescent described the challenge of actually telling people because it forced her to face the reality of the situation. When she told people, she would realize, "that I have a disease or something. Like it's really serious." When she was asked how that made her feel, she responded, "Scared." In addition, these adolescents seemed more willing to be open with both with the researcher and other individuals in their own lives, especially close friends. One adolescent described sharing her diagnosis with friends in the following way, "I'd just say that I have MS. And they'd say oh what's that. And I'd say, oh well it's just an infection in my brain and in my spine. That's what I thought it was." These descriptions demonstrate that adolescents with early-onset MS do experience the first task of mourning outlined by Worden.

Another task of mourning identified by Worden (2002) is experiencing the pain of grief. This was represented in the present study by the sub-category 'manifestations of grief'. According to Worden (2002), it is necessary to work through the pain of grief or it may reveal itself in other ways (e.g., behaviourally, socially). In the data from this study,

it seemed quite common for the pain of grief to be expressed not only emotionally, but also physically, socially, and cognitively. For example, one participant described her struggle with the pain of grief in the following way: "...I keep more to myself. I don't quite share everything everything with everyone. Or, and I'm I don't know how to express myself. Like I'm darker inside, so to say." In fact, it could be argued that it would be quite natural for children and adolescents to express these painful emotions in other ways. Corr (2000) suggested that these individuals may lack experience with strong and difficult emotions. They may have difficulty identifying and/or expressing these emotions. The present study supports this supposition as it demonstrated that adolescents express grief through the emotional, behavioural, cognitive, and social domains. In addition, Corr (2000) indicated that they may not be permitted, or given the opportunity, to express these grief reactions. During the last couple of interviews for this study, the researcher asked the parent participants if they thought their children were expressing grief in any way. Most parents were unfamiliar with how grief could be manifested and did not believe their children were expressing it in any way. However, the results of this study demonstrated that adolescents with MS do experience grief and also must work through the pain associated with the loss.

An additional task of mourning outlined by Worden (2002), is adjusting to an environment in which the loss is absent. He described this task as having three components: 1) external adjustments, 2) internal adjustments, and 3) spiritual adjustments. For some of the adolescents with MS, the external adjustments were experienced through the realization that they cannot participate in all of the same activities they once did, or to the same extent. As one participant stated, "I can't really do

everything that others would do because it might affect my health in a negative way, and interfere with my injections and all that." As another participant described, it may also be experienced through school absences due to medical appointments, flare-ups of the disease, or medication side-effects. "Well, I like school, but since it's grade nine and it's really hard, so I miss a day and I fall really behind....Especially when I missed that week of school, I fell really behind." Internal adjustments experienced by the individual often include the challenge of adjusting their own sense of self (Worden, 2002). This struggle was represented in the data by the 'loss experiences' component 'identity shift'. When the loss is closely tied to the individual's sense of self, as it is in chronic illness, there can be a very real threat to self-esteem. Several participants identified the reality of this statement. For example, one participant reported:

> ...she just felt more of a side show, more of a freak show because the odd time she'd end up taking a cane to school, or you know they'd point fingers and laugh or point fingers and say you're faking or you know. And I know that really bothered her.

Experiencing spiritual adjustments was less represented in this study. Nonetheless, it was apparent through the 'secondary losses', in particular the loss of assumptions about the world. Worden (2002) argued that death can challenge one's fundamental values and philosophical beliefs. The results of this study suggested that adolescents who are diagnosed with chronic illness also face this struggle. For example, one participant described her own personal battle with feeling negative about life:

Just everyday life, I don't really have faith anymore, I don't. Even though I

should, and then I go to church, and I don't know. I believe in God, I pray to God,

but I don't know, I 'm just out of faith, like you would be out of breath.

In order to successfully complete this task of mourning, individuals must make these

necessary adjustments. Some participants in this study demonstrated successful

completion where as others did not. It is quite apparent, however, that even adolescents

diagnosed with MS also experience the task of adjusting to an environment in which the

loss is absent.

Finally, Worden (2002) identified the task of moving on with life after the loss.

He argued that individuals need to find a way to remember the death of a loved one,

while also moving on with life. This concept was best demonstrated in this study through

the sub-category 'manifestations of acceptance'. The idea of memorializing the loss does

not seem to translate well to the grief experience of adolescents with MS. It is

challenging to express how one would memorialize a part of oneself. However, it could

be proposed that the 'day-by-day' mentality suggested by several participants is a way to

remember good health on the good days. In a manner of speaking, it is a way to

memorialize lost health by appreciating it when it is present, while also being realistic

about the unpredictability of the disease. As one adolescent expressed it, "So, it was just

kind of me dealing with it day to day, more than me dealing with it down the road, so it

make it a lot easier." The idea of moving on with life, however, was expressed much

more frequently by participants. During the theory verification interview, another

adolescent expressed acceptance in this way, "The motto for MS, this too shall

pass....Because even when you back into that grief stage because you're going into

relapse or things are going crappy, or whatever, you know that, even if that, this too shall pass." This study demonstrated that the grief experience of adolescents with MS also involves the task of moving on with life. However, the memorialization of a loss of self due to chronic illness seems to be manifested in a more abstract way than loss due to death.

The present research has both reinforced and added to the understanding of Worden's (2002) four tasks of mourning. It has been identified that adolescents diagnosed with MS do experience a grief process which is comprised of the four tasks of mourning. However, the results of this study expand on the traditional understanding of these tasks in several ways. First, the denial experienced in the grief process can sometimes be facilitative in moving towards acceptance. Second, the pain experience for these adolescents is not just manifested emotionally, but also behaviourally, cognitively, and socially. Third, there are some experiences within this process that seem to be unique to individuals with chronic illness. This was demonstrated by memorializing the loss. These variations in the grief process have implications for the role of counsellors in treatment, which will be discussed further in Chapter Six.

Grief and Adolescent Development

Previous research has suggested that the grief process and developmental tasks are interconnected in many ways (Worden, 1996). An adolescent's self-esteem, sense of belonging, and feeling of control may be threatened by grief. The descriptions of many participants verified this statement. For example, some adolescents described feeling a loss of control because of the medications they were required to take. Other participants described a threat to the adolescent's sense of belonging when the adolescent withdrew

from peers because of fear and uncertainty about the future. However, past research has overlooked how loss experienced in these developmental tasks can actually contribute to the grief. The results from this study suggested that these adolescents may actually experience a loss in these developmental areas. As such, these developmental tasks are not just threatened by the grief experience, but a temporary loss in these areas may contribute to grief itself. For example, one parent described an adolescent's struggle with identity in the following way, "She was tired and she missed a lot of school. And that's, everybody thinks that she, well she even thinks that she's slow or dumb or whatever." This adolescent experienced grief reactions in response to this challenge to identity. Therefore, it is not sufficient to just say that developmental tasks are threatened by grief, but to also add that these tasks can contribute to the grief experience.

Grief and Peer Relationships

Worden's (1996) research on children's and adolescents' grief after the loss of a parent suggested that peer relationships are impacted by the experience of loss. His results demonstrated that peers can play both a positive role and a negative role in the experience of grief. Worden's findings were found to be similar to those of this study. The peers of adolescents with MS sometimes complicated the grief process by adding to the 'medication-peer tug of war', by abandoning the relationship, or causing increased worry. On the other hand, peers were able to provide important support, an opportunity to talk about the struggles of MS, and a distraction from an otherwise overwhelming experience. Worden (1996) also gave several specific examples of the experiences youth had with their peers following the death of a parent. Surprisingly, these examples were reproduced within this study as well. This suggests that in spite of the type of loss, peer

relationships can both inhibit and facilitate the grief process for children and adolescents. Since peers can play such an influential role in the grief experiences of children and adolescents, it is important for this to be taken into consideration when providing treatment and support for these individuals. This will be explored in more detail in Chapter Six.

Grief and Chronic Illness

Researchers have argued that the experience of grief resulting from loss due to chronic illness is tangibly different from loss due to death or terminal illness (Kahn, 1995; Sharoff, 2004; Werner-Beland, 1980). As this study did not compare chronic illness to other types of losses, it is not possible to verify this difference. However, the results of this grounded theory do verify the various grief experiences identified by these researchers. This includes the strong anger reactions experienced by some participants. Participants also described threats to self-esteem and identity which were similar to those identified in previous studies. Therefore, the data gathered in this study support previous findings on grief in chronic illness.

Researchers have also suggested that loss from chronic illness can be ambiguous in nature (Boss & Couden, 2002). For example, as in the experience of MS, the progression of the disease may be unknown, relapses arise unexpectedly, or the individual may look normal to others while suffering from the illness in silence. The idea of ambiguity was reinforced in this study through the participants' descriptions of the diagnosis process. Participants repeatedly described in length the numerous tests that were undergone, the diagnosis of elimination, and the numerous emotions experienced in the process. In the words of one participant:

> Umm, well it was really scary because of the, the first initial thought was a tumour. And so, then when they said it wasn't a tumour and it might be MS, it was almost a relief as opposed to devastating because it could've been so much worse. Or in our view I guess, so much worse. And umm, and then it was, I guess confusing and still scary because they couldn't confirm it. I mean they just said well this is what it could be, we won't know for awhile. So then you're left with the unknown.

Ambiguity was also demonstrated through the difficulty peers had in understanding the effects of MS when the symptoms were not visible. One adolescent described her struggle with this kind of ambiguity in the following, "…you're at a club and it gets too hot, and you have to go sit down, and your friends all get mad at you and then you get into big fights because they're all mad." The concept of ambiguous loss does in fact seem to apply to loss due to chronic illness. It helps to broaden ones understanding of the unique loss experienced from chronic illness and how that may be manifested in the grief process.

Lewis (1983) proposed that loss due to chronic illness was cyclic in nature. Not only does the individual with chronic illness experience loss of health, but also numerous other associated losses. She suggested that grief accompanies each of these secondary losses. The category 'loss experiences' identified in this study supports the presence of a core loss and associated losses. Participants' descriptions also suggest that adolescents with MS express grief reactions in response to these additional losses. For example, as many of these adolescents experienced loss of skills and abilities, their identity was

challenged. They were required to mourn the loss of these parts of themselves. One adolescent described this loss experience in the following way:

> Umm, well not being able to do the things I used to be able to do has really affected it because a lot of my friends I hung out with at that one point in time we all played on the basketball team and everything. So that's another reason why I lost so many friends because all of my friends were in that circle of jocks and stuff so when I got sick I couldn't play anymore. And so that kind of that kind of ruined that.

This cyclic model of grief helps one to understand the unique experience of losing something that is part of oneself and of which one can be reminded of throughout the lifespan. This is especially critical in understanding the grief experience of adolescents who are just beginning to develop their sense of identity, their dreams for the future, and exploring various social roles. It also assists in understanding how the unpredictability of a relapsing-remitting disease can impact the grief process.

Finally, several researchers have presented a chronic sorrow model (e.g., Eakes, Burke, & Hainsworth, 1998), which takes into account both the ambiguous and cyclic nature of grief from loss due to chronic illness. The results of this study offer support for most components of this model, including the major 'loss experience', the resulting 'grief experience', and the recurrence of grief as a consequence of secondary losses. However, support was not found for the progressive nature of grief as described by Burke, Hainsworth, Eakes, and Lindgren (1992). In fact, one participant described the opposite:

Yeah, you level up on the acceptance that much more each time. You'll go back into the grieving, but not as deep, if that makes sense. You'll come out higher on the acceptance side.

Eakes, Burkes, & Hainsworth (1998), also reported other studies which do not support the progressive nature of grief in this model, nonetheless they continue to define chronic sorrow in this way. The results of this study suggest that further study needs to be done into the progressive nature of chronic sorrow, and appropriate changes to the definition be made.

Summary of Contributions to Grief Literature

In summary, this study supports current grief research in a number of ways. In particular, it reinforces the four tasks of mourning identified by Worden (2002). This demonstrates that adolescents do experience grief in response to a diagnosis of MS. The interconnection between grief and developmental tasks was also verified by this study. Recognizing this relationship assists in understanding the grief experiences of children and adolescents. Peer relationships were also identified to play a role in the grief experiences of adolescents with MS. Therefore, not only is the individual context important, but the social context is also essential in understanding the grief process. Finally, this study confirmed the ambiguity of loss due to chronic illness, in addition to the cyclic nature of grief due to numerous associated losses. Results derived from this study help in understanding the unique experience of grief and loss from chronic illness like MS for adolescents. Overall, many theories and perspectives about grief and chronic illness are supported by this grounded theory.

This study also makes several contributions to the current literature on grief.

First and perhaps most importantly, this study helps to interconnect a number of theories and perspectives on grief and chronic illness. Combining Worden's (2002) four stages of mourning with the theories on ambiguous loss and cyclic grief creates a more complete representation of grief and loss for adolescents with MS. It is also noteworthy that Worden's model appears to fit with loss due to chronic illness, and not just loss due to death. The interconnection between grief and developmental tasks was also expanded on by this study. The results demonstrated that experiences in these two areas can feed into and influence the other. Finally, the progressive nature of grief, as presented in the chronic sorrow model, needs to be re-examined and modified based on the research results from this study. In conclusion, the results of this study support the presence of grief following each diagnosis of MS in adolescence, and highlight some of the unique experiences associate with it. Future empirical studies will help to develop a more comprehensive theory on grief and chronic illness in childhood and adolescence.

Conclusion

This chapter presented a discussion of the contributions and enhancements of the results from this study to existing literature on grief, chronic illness, psychosocial development, and peer relationships. One of the most important contributions of this research was the identification of the grief experience as a central issue in the psychosocial development of adolescents with MS. Previous literature has often overlooked this concept in understanding the experiences of children and adolescents with chronic illness. The theory presented in this thesis proposes that grief plays an integral role in understanding the psychosocial wellbeing of these individuals. In addition, it provides a framework for understanding the individual's social behaviours

and the role peer relationships can play in the process. This grounded theory offers the first theoretical framework for understanding the role of peer relationships in the psychosocial development of adolescents with early-onset MS. The following chapter presents the implications and limitations of this research.

CHAPTER 6: CONCLUSION

The purpose of this study was to explore the role of peer relationships in the psychosocial development of adolescents with MS. The methodology employed provided opportunity to gather detailed accounts of the experiences of these adolescents with their peers. The grounded theory developed out of the data provides insight into the nature of these relationships. In addition, it provides a framework for conceptualizing psychosocial development in this population. The following chapter will address the implications and limitations of this research in more detail. This grounded theory has the potential for the following benefits: 1) increasing understanding of the experiences of individuals with early-onset MS, 2) guiding the development of counselling programs, interventions, and services for children and adolescents with early-onset MS, and 3) guiding future research in this area. The first of these was addressed in Chapter Five, and the latter two will be addressed in more detail in this chapter. Implications are discussed in terms of the potential roles for counsellors, and the development of interventions and services for these adolescents and their families. Limitations are discussed in terms of methodological issues. Finally, suggestions for future research conclude the discussion for this chapter.

Research Implications

The results of this study have many implications for the role of counsellors and the development of services for adolescents with multiple sclerosis. First, counsellors can use the results of this study to contribute towards an interdisciplinary team of healthcare providers. Second, counsellors can act as a liaison with schools to facilitate the adolescent's adaptation to the school environment. Finally, through the use of therapeutic interventions, counsellors can promote healthy psychosocial development of the

adolescent with MS. Counsellors can play a valuable role in the treatment and care of adolescents with MS.

Counsellors in an Interdisciplinary Team

The results of this study have implications for the role of counsellors within an interdisciplinary team. Previous research has identified the value of an interdisciplinary team in healthcare (Drotar, 2002). In particular, counsellors and psychologists were deemed to be important members of this team (Farmer et al., 2004). There are several ways that counsellors and psychologists could use the information gathered out of this study to contribute to an interdisciplinary approach to healthcare. Specifically, counsellors could use this information to enhance interdisciplinary care for adolescents with MS. Drotar (2002) has suggested there is opportunity for mutual enrichment of knowledge and perspectives within the members of the interdisciplinary team in that they can benefit from each other's expertise. Counsellors can use the information from this study to help educate physicians involved in the adolescent's treatment. For example, they can help the physicians to understand the grief reactions of the adolescents to the diagnosis, and the potential impact these reactions may have on medical treatment. It is also important for counsellors to help educate physicians on the developmental importance of peer relationships. For example, counsellors can help physicians to recognize the struggle adolescents have with balancing their medications and their peer relationships. Then, by working with the adolescent and the physician, they can assist in finding a workable compromise so neither the medical treatment or peer relationships are neglected. Counsellors can also contribute to the interdisciplinary team by screening for unhealthy or prolonged manifestations of grief. It is possible that other healthcare

professionals may overlook this psychological impact of disease. Therefore, counsellors can inform the treatment team about the potential consequences this can have on the adolescent's treatment compliance, desire to access support, and overall wellbeing. In addition, other suggestions for managing the care of adolescents with MS may be offered (e.g., counselling interventions). By becoming knowledgeable about the psychosocial development of individuals with early-onset MS, counsellors would be valuable members on an interdisciplinary care team for these youth.

Counsellors as Liaison with Schools

Counsellors can also act as a liaison between schools and the healthcare system. For example, counsellors can help educate school staff on the illness. If the school staff is more aware of the school challenges these adolescents face, they will be better equipped to address academic needs. By facilitating this process, counsellors can work with schools to minimize the negative impact of school related problems on psychosocial development. In addition, counsellors can help to facilitate the development and maintenance of healthy peer relationships. The data from this study suggested that talking with peers was important in developing disease acceptance. As such, counsellors can work with adolescents to educate their peers about the disease to increase understanding. For example, counsellors may collaborate with teachers to present the adolescent with opportunities to incorporate learning about MS into class assignments and presentations. Consequently, peers who have a clearer understanding of the disease would be in a better position to provide the valued support and understanding that adolescents with MS desire.

Counselling Interventions

There are many possibilities for counsellors to develop interventions for adolescents with MS and their families. According to Corey (2001), "the central function of counselling is to help clients recognize their own strengths, discover what is preventing them from using their strengths, and clarify what kind of person they want to be" (p. 37). It is the role of the counsellor to help the client develop skills, tools, and personal insights to alleviate problems and move toward healthy living. As such, counsellors could contribute towards the psychosocial development of adolescents with MS by implementing interventions which address the adolescents' and families' needs, and builds on their strengths. Individual counselling may address such issues as grief, social skills and coping skills. Family counselling may address such issues as parental support and education. Developing interventions in these areas would facilitate the psychosocial development of adolescents with MS.

Individual counselling interventions may focus on psychosocial development, addressing issues including grief, social skills, and coping skills. The core theme of grief identified in this study highlights the need for addressing the grief of adolescents. As previously mentioned, grief is often an unknown experience for these individuals and may be quite overwhelming. In addition, because chronic illness does not carry the typical markers of loss, the adolescent may not receive permission or support to grieve. Therefore, adolescents with MS could benefit from therapeutic interventions which help them to process the various manifestations of grief. Counsellors can also work with adolescents who struggle with developmental issues such as self-esteem, identity, belongingness, and other associated losses. Another goal for individual counselling may

be providing cognitive therapy. Many of the participants identified adolescents' expectations of being rejected by their peers due to the stigma of disease. However, when asked directly if they ever experienced this rejection, most adolescents replied in the contrary. This suggests that these adolescents have adopted mistaken beliefs which could be disputed through cognitive therapy. Finally, counsellors can assess the social needs of the adolescents with MS and provide skills training where needed. This may include developing healthier coping strategies, improved social skills for interacting with peers, and education about grief and how it may impact their peer relationships. For example, adolescents reported withdrawing from peers because of their own grief experience. Counsellors can help these adolescents find more effective coping strategies that do not jeopardize their peer relationships. These new coping strategies may restrict the influence of negative peer interactions on the grief process. The results of this study reveal many opportunities where counsellors can contribute towards the psychosocial development of adolescents with MS through individual counselling.

Counsellors can also address the psychosocial development of adolescents by addressing the family system. Several parents described their own struggle with accepting the illness. Previous research suggested that parents of children and adolescents with chronic illness experience recurring grief following diagnosis (e.g., Boss & Couden, 2002; Langridge, 2002; Worthington, 1989). When parents are experiencing their own grief, they may be less likely to provide adequate support for the adolescent. In addition, adolescents in this study talked about the guilt they had for worrying their parents. Family counselling interventions are important in helping the family system process the loss due to diagnosis of MS. Specifically, these interventions may include parental

support and education programs. It would be beneficial for counsellors to help educate parents on the grief process so that parents are more equipped to support their adolescents through this process. Parents could also be educated about the potential for struggles with peer relationships. Once parents are informed of these challenges, they would be more equipped to provide the support needed by adolescents with MS. It would also be beneficial to provide grief counselling to parents. By giving parents somewhere safe to process their grief, it is anticipated that it would minimize the impact of parental grief on the psychosocial wellbeing of the adolescent with MS. Finally, within family counselling sessions, counsellors can help to establish an open dialogue in which the parent and adolescent could communicate with each other about the MS. This could prove to be beneficial in helping parents and children understand each others' grief reactions, loss experiences, and provide support for each other. The findings from this study create numerous opportunities for counsellors to create interventions for helping families cope with the diagnosis of MS.

Limitations

The limitations of this study relate primarily to methodological issues. Two of these issues were mentioned in Chapter Four: data source and language barrier. Additional limitations include gender composition of the sample population and the generalization of the results. Each of these limitations will be addressed in more detail in the following discussion.

Source of Data

It was identified in Chapter Four that both adolescent and parent perspectives were used as sources of data. Previous research led the researcher to believe that parents

would be a valuable source of information as they are the adolescents' primary caregivers. Adolescents may be so immersed in the situation they may not be able to identify differences or changes, or at least not in detail. They may be more likely to describe their experiences in the moment. Parents, on the other hand, were thought to be more likely to describe experiences in terms of the overall context. However, it was discovered in this study that parents had limited knowledge about the peer relationships of their children. When parents identified that they did not know about their adolescents' peer relationships, they often switched the focus of the interview onto their involvement in care. Additionally, the researcher struggled with allowing the parent to share their own story while maintaining a focus on peer relationships. As a result, the role of peer relationships in the psychosocial development of adolescents with MS may not have been fully uncovered.

There are several possible explanations for why parents were unaware of many of their children's peer relationships. First of all, most of the adolescents in this study were at the older end of adolescence. Developmentally, this would suggest that many had already made the transition from disclosing to parents to disclosing to peers. These older adolescents are more likely to keep their peer relationships separate from their parents as a way to develop independence. Another possible explanation is that there really was nothing for the adolescent to tell parents. If the adolescent did not experience any disruptive changes to peer relationships, there would not be anything to share with parents. The consequence of the lack of parental knowledge may be that the category 'relationship dynamics' was not fully developed. However, with that said, the researcher believes that the rich detail provided in many of the adolescents' descriptions was

sufficient in developing the category 'relationship dynamics', even without the parents'

insight.

Language Barrier

A language barrier was also identified in Chapter Four as a potential limitation to

this study. It was identified that several participants were immigrants to Canada.

Consequently, their grasp of the English language was varied. The challenge of language

came into play during the interviews several times. As previously discussed, one

adolescent was required to translate for her parent. The language barrier seemed to limit

the amount of information the participant shared as this was the shortest interview. The

researcher was also required to fill in and verify the word choice of another participant in

order to clarify what the participant was trying to say. As much as the research tried to

avoid it, this may have occasionally coloured the participant's descriptions. The language

barrier also came into play when interpreting the results of this study. Participants who

struggled with language were less concise in their descriptions. Consequently, it was

more challenging to understand what the participant was trying to communicate.

Therefore, the researcher was more cautious with interpreting these participants' stories.

In general, there is little evidence to suggest that the language barrier drastically impacted

the results of this study. However, it was still necessary to identify the ways in which

language may have played into the interview and data analysis processes.

Gender Composition

The participants for this study included six adolescents (5 female; 1 male) and six

parents (5 female: 1 male). After the age of 12, research has found the ratio of male to

female early-onset MS patients to range from 1:3 to 1:4 (Ghezzi et al., 1997; Kalb et al.,

1999). This suggests that the female adolescents with MS were slightly over-represented in the current study. Parent participants were also over-representative of mothers versus fathers. Nonetheless, the results of this study were able to account for the experiences of all participants and did not seem to be gender specific. However, due to the preponderance of female participants, it is possible that more, or different, themes may have been identified if more males had participated. Unfortunately the number of male adolescents with MS was out of the researcher's control. The male who participated was the only one available from the sample MS Clinic. In order to obtain a more representative sample, it would be necessary to include participants from multiple sites. There are several explanations why the parent sample was female dominated. First, several of the adolescents were in single parent families. Therefore, the mother was the only one available to participate. In regards to the rest of the families, it seemed that the parent who provided the most care for the adolescent with MS was the one to participate in the interview. As such, in the remaining two-parent households several mothers and one father volunteered to be involved in the study. It would be interesting to discover what kind of difference, if any, involving both parents in a study like this would have on the results.

Generalization of Results

The theory developed from this research is substantive in nature. That is, the grounded theory is focused on a specific group of people in a specific place (e.g., adolescents with MS from the Calgary MS Clinic) (Strauss & Corbin, 1998). Due to the narrow focus of this research, the results should not be generalized beyond the participants of this study. For example, in its current state, this theory cannot be expected

to generalize to all children and adolescents with chronic illness. While the results of this study may apply beyond the experiences of this specific sample, additional studies will need to be done in order to increase the generalizability of this theory. However, this limitation does not negate the real value of the grounded theory developed out of this research. According to Strauss and Corbin, "the real merit of a substantive theory lies in its ability to speak specifically for the populations from which it was derived and to apply back to them" (p. 267).

Future Research

There are several opportunities for future research as a result of the findings from this study. Some of these opportunities come from the limitations identified in this study. Specifically, research could address the source of data, gender composition and the generalizability of the results. Other opportunities arise out of the implications of this study for counsellors. Future research could explore the various roles counsellors could take in treating adolescents with early-onset MS. The following is a discussion of these possible directions for research.

The realization that parents cannot always provide useful information about their children has implications for future research. Specifically, this seems to apply towards the use of parents in understanding the nature of peer relationships. Future research may instead want to consider involving peers of the adolescent population under study in the research. Asking the peers directly about their experiences with the adolescents has the potential of providing a more useful perspective for studying peer relationships. Peers are involved in the relationship; therefore they would be able to offer a direct view into the nature of these relationships.

It would also be interesting to investigate the perspectives of both parents on the experiences of their children. The parent participants in this study were primarily mothers; however fathers may also offer insight into their child's life. In fact, one mother recognized that her spouse would likely offer a differing view on their adolescent's experiences with MS and peers. It is possible that youth share different experiences with different parents. Consequently, each parent would be able to offer a unique view into their child's experiences. By involving both parents in the data collection, the researcher may be able to obtain greater depth and breadth in the data.

Future research could also contribute greatly to this area of study by exploring the generalizability of this theory to a broader population of youth with MS and youth with chronic illness in general. First, a variety of MS Clinics need to be studied in order to discover if the results of this study are generalizable to early-onset MS patients both nationally and internationally. In addition, researchers should consider including participants from both rural and urban centers. This may impact the nature of results due to the ease of accessing support services. Second, a broader age range of participants should be included. The participants in this study were primarily diagnosed in middle to late adolescence. In order to broaden the applicability of this study, it would be necessary to see if the theory holds true for all children and adolescents with early-onset MS. Third, children and adolescents with other chronic illnesses could also be studied. It would be interesting to explore if other youth with chronic illnesses experience a similar grief experience. In addition, the role of peer relationships in that experience should also be studied. There are many areas to explore in order to discover the broader applicability of this grounded theory.

Finally, several directions for future research arise out of the implications of this study to the role of counsellors. First, future research can focus on the effectiveness of individual counselling on psychosocial development of adolescents with MS. This counselling may address issues like grief, coping skills development, and building and maintaining supportive relationships with peers. Each of these issues was identified to be key to psychosocial development. Most psychosocial interventions available for youth with chronic illness have not been evaluated (Bauman et al., 1997). Therefore, future research would do well to study the effectiveness of these interventions for the development of youth with chronic illness. Second, a group counselling program for youth with MS could be developed. The results of this study suggest that positive interactions with peers were an important source of support and facilitate movement through the grief process. In addition, participants described the value of mutual understanding and shared experience. As such, creating a group counselling program for individuals diagnosed with early-onset MS could assist in developing acceptance of the loss of health. This program could also help to build valuable peer relationships. The role of future research would then be to explore the effectiveness of such a program in meeting these goals. Finally, the development of a psycho-education and group therapy program for parents could also be explored through future research. This study did not address the role of parents in detail. However, it became apparent to the researcher that many of these parents were unaware of their adolescent's grief reactions. They also expressed many of their own struggles with accepting the illness and the adolescent's reactions to it. Consequently, another direction for future research would be to explore in greater detail the experiences of parents of adolescents with MS. These experiences could

be addressed within a group therapy setting. In addition, a psycho-education component could help to educate parents about the grief experiences of their children, and offer suggestions for providing support. The effectiveness of such a program on the overall wellbeing of the adolescent and his or her family could be assessed in future studies.

It has been demonstrated that there are numerous opportunities for future research which have developed out of this study. The goal of this future research is to expand on the findings and implications of the grounded theory developed from in-depth interviews with adolescents with MS and their parents. Some of this research will address the limitations identified in this study. Others will hopefully broaden the applicability of this theory. Finally, through research, counselling interventions can be assessed in regards to their effectiveness for this population. All in all, continued research into the psychosocial development of adolescents with MS will increase understanding about their experiences and guide the development of treatment.

Conclusion

The goal of this study was to explore the role of peer relationships in the psychosocial development of adolescents with MS. This was accomplished by addressing the nature of experiences with peers and the impact of the individuals' social skills on the relationship. The grounded theory developed from the interview data provides a paradigm for understanding the interconnection between psychosocial development and peer relationships. Furthermore, the theory provides a more general model than in previous research for understanding the psychosocial wellbeing of these adolescents. Specifically, it proposes that the psychosocial states of the youth with MS could be explained through grief concepts. The theory suggests that if the adolescents have 'loss experiences' due to

the loss of health and associated secondary losses, the grief process will ensue. This grief process is expressed through 'manifestations of grief' and 'manifestations of acceptance'. Peer relationships were further determined to be involved in this experience of grief. The 'relationship dynamics' took on many forms, sometimes contributing towards the grief, other times suffering as a result of the grief. Peers became involved in the grief process through the 'medication-peer tug of war', by providing 'supportive relationships', by being involved in a 'shift of friendships', through the adolescent's 'dealing with others' worry', 'talking about MS', and finally 'acting as if'. The theory suggests that positive peer interactions facilitate the adolescent's movement through the grief process. However, negative peer interactions generally contribute towards the grief process by maintaining 'manifestations of grief'. In addition, they could result in the adolescent cycling through the grief process again and again by adding to the secondary losses. The importance of understanding the role of grief in the psychosocial development of these adolescents is particularly noteworthy.

This grounded theory contributes towards existing literature and provides direction for future research. One of the key contributions of this study seems to be the identification of grief in the experiences of these adolescents. It provides new insight into understanding their psychosocial wellbeing. In addition, the results help to clarify the mixed reviews on the nature of peer experiences for individuals with chronic illness. It does this by offering an explanation for the presence of both positive and negative peer experiences and how these contribute towards the adolescent's wellbeing. Finally, the most significant contribution of this research is the provision of the first theoretical paradigm for understanding the psychosocial development of adolescents with early-

onset MS. This model can now act as a foundation for guiding future research into this virtually unexplored area of study. By forging a deeper understanding of adolescents' experiences of MS, both peer relationships and grief have been shown to play a significant role in understanding their psychosocial development.

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Appendix A

Consent Forms

ADULT CONSENT FORM

TITLE: **Psychosocial development of individuals diagnosed with early-onset Multiple Sclerosis: The role of peer relationships**

SPONSOR: SSHRC – Canada Graduate Scholarship – Master's

INVESTIGATORS: *Jean K. Mah, MD, FRCPC (Principal Investigator)*

Jennifer Thannhauser (Master's Student)
Kris Magnusson, PhD (Thesis Supervisor)
Jackie Bakker, MD, FRCPC (MS Clinic, Calgary)
Walter Hader, MD, FRCPC (MS Clinic, Saskatoon)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

Multiple Sclerosis (MS) is a chronic, neurological disease which has primarily been understood to develop in early adulthood. However, it is becoming increasingly apparent that a small proportion of those afflicted with the disease have a much earlier onset. Children and adolescents diagnosed with the disease face unique challenges. Specifically, MS may have an impact on the social and emotional development of the youth with the disease. Unfortunately, very little is known about the psychosocial impact that a diagnosis of MS may have on children and adolescents. Therefore, it is only through research that more will be learned about MS in children and adolescents. Research is needed to increase our understanding of the emotional and social needs of children with MS, and to develop appropriate resources (e.g., counselling programs) to meet those needs.

It is proposed that 10 – 12 parent-youth pairs will be recruited from MS Clinics in Calgary, AB and Saskatoon, SK. Youth must be diagnosed with MS between their 10th birthday and the end of their 18th year, though they may be up to the age of 20 years. Data will be obtained through an interview format. Interviews will be arranged with the child/adolescent with MS and at least one parent or guardian. Your candid and thoughtful reply will help inform others of the experiences of youth with MS. It is anticipated that each interview will take approximately one hour. There will be separate interviews for

you and your parent/child. Interviews will be transcribed and analyzed for common themes.

WHAT IS THE PURPOSE OF THE STUDY?

The focus of this study will be to explore the nature of peer relationships and social behaviours in the psychosocial development of children and adolescents diagnosed with early-onset MS. Specifically: 1) What are the peer social experiences of children and adolescents diagnosed with early-onset MS? And 2) Do the social behaviours of children and adolescents with early-onset MS impact their peer relationships?

WHAT WOULD I HAVE TO DO?

You will be required to take part in a one hour interview. Three or four participants will be randomly selected for a follow up one hour interview. This follow up interview will be used to check the personal relevance of the themes identified in the data analysis. The study is expected to last 7 months, though you are only expected to participate for the length of the initial interview and potential follow up interview.

WHAT ARE THE RISKS?

There are no forseen risks of physical or emotional harm to you.

WILL I BENEFIT IF I TAKE PART?

There are no direct benefits to participating in this study.

The information we get from this study may help us to provide better treatments in the future for patients with MS.

DO I HAVE TO PARTICIPATE?

Your participation is completely voluntary and you are free to withdraw, without repercussions, at any point during the interview.

If new information becomes available that might affect your willingness to participate in the study, you will be informed as soon as possible.

WHAT ELSE DOES MY PARTICIPATION INVOLVE?

There are no additional requirements of you.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

Participating in this study will have no financial cost or benefit to you.

WILL MY RECORDS BE KEPT PRIVATE?

You will be contacted by the MS Clinic Coordinators/neurologists so as to maintain your confidentiality until the time of your decision to participate. If you are interested in participating, you will consent to the release of your personal contact information by the MS Clinic to the student researcher, or will contact the student researcher directly.

The interview will be conducted and transcribed by the student researcher. The transcript will only be marked with an ID number. Your responses will be treated with utmost confidentiality. No personally identifying information about you will be given in the results of this research. Quotes or examples will be used from the transcribed interview data in the written report; however, names will be omitted and any other potentially identifying information will be changed. For example, personal pronouns (e.g., he, she) will be randomly assigned to protect the anonymity of the respondents or pseudonyms will be utilized. Only the researchers and the University of Calgary Conjoint Health Research Ethics Board will have access to participant information, so as to prevent unauthorized collection, use or disclosure of your personal information.

HOW WILL THE RESULTS BE USED?

Upon completion of the study, research findings will be available through The University of Lethbridge Library. The results may also be used in future presentations and/or publications. Hardcopies will be available to participants upon request and summaries will be sent to participating MS Clinics.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Jean Mah, MD, FRCPC (403) 943-7817

or

Dr. Kris Magnusson, PhD Email: kris.magnusson@uleth.ca

or

Jennifer Thannhauser (403) 613-1399; jennifer.thannhauser@uleth.ca

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services,

University of Calgary, at 220-3782. Also, you may contact Rick Mrazek, Chair Human Subject Committee, Faculty of Education, University of Lethbridge, at (403) 329-2452.

Participant's Name	*Signature and Date*

Investigator/Delegate's Name	*Signature and Date*

Witness' Name	*Signature and Date*

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

The University of Lethbridge Department of Education Human Subject Committee has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

PEDIATRIC CONSENT FORM

TITLE: Psychosocial development of individuals diagnosed with early-onset
Multiple Sclerosis: The role of peer relationships

SPONSOR: SSHRC – Canada Graduate Scholarship – Master's

INVESTIGATORS: Jean K. Mah, MD, FRCPC (Principal Investigator)

Jennifer Thannhauser (Master's Student)
Kris Magnusson, PhD (Thesis Supervisor)
Jackie Bakker, MD, FRCPC (MS Clinic, Calgary)
Walter Hader, MD, FRCPC (MS Clinic, Saskatoon)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your child's participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

Multiple Sclerosis (MS) is a chronic, neurological disease which has primarily been understood to develop in early adulthood. However, it is becoming increasingly apparent that a small proportion of those afflicted with the disease have a much earlier onset. Children and adolescents diagnosed with the disease face unique challenges. Specifically, MS may have an impact on the social and emotional development of the youth with the disease. Unfortunately, very little is known about the psychosocial impact that a diagnosis of MS may have on children and adolescents. Therefore, it is only through research that more will be learned about MS in children and adolescents. Research is needed to increase our understanding of the emotional and social needs of children with MS, and to develop appropriate resources (e.g., counselling programs) to meet those needs.

It is proposed that 10 - 12 parent-youth pairs will be recruited from MS Clinics in Calgary, AB and Saskatoon, SK. Youth must be diagnosed with MS between their 10th birthday and the end of their 18th year, though they may be up to the age of 20 years. Data will be obtained through an interview format. Interviews will be arranged with the child/adolescent with MS and at least one parent or guardian. Your candid and thoughtful reply will help inform others of the experiences of youth with MS. It is anticipated that each interview will take approximately one hour. There will be separate interviews for you, the parent, and your child. Interviews will be transcribed and analyzed for common themes.

WHAT IS THE PURPOSE OF THE STUDY?

The focus of this study will be to explore the nature of peer relationships and social behaviours in the psychosocial development of children and adolescents diagnosed with early-onset MS. Specifically: 1) What are the peer social experiences of children and adolescents diagnosed with early-onset MS? and 2) Do the social behaviours of children and adolescents with early-onset MS impact their peer relationships?

WHAT WOULD MY CHILD HAVE TO DO?

You and your child will each be required to take part in a one hour interview. Three or four participants will be randomly selected for a follow up interview. This follow up interview will be used to check the personal relevance of the themes identified in the data analysis. The study is expected to last 7 months, though you are only expected to participate for the length of the initial interview and potential follow up interview.

WHAT ARE THE RISKS?

There are no forseen risks of physical or emotional harm to you or your son/daughter.

ARE THERE ANY BENEFITS FOR MY CHILD?

There are no direct benefits to participating in this study.

The information we get from this study may help us to provide better treatments in the future for patients with MS.

DOES MY CHILD HAVE TO PARTICIPATE?

Your participation, and your child's participation, is completely voluntary and you are free to withdraw, without repercussions, at any point during the interview.

If new information becomes available that might affect your willingness to participate in the study, you will be informed as soon as possible.

WHAT ELSE DOES MY CHILD'S PARTICIPATION INVOLVE?

There are no additional requirements of you or your child.

WILL WE BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?

Participating in this study will have no financial cost or benefit to you.

WILL MY CHILD'S RECORDS BE KEPT PRIVATE?

You will be contacted by the MS Clinic Coordinators/neurologists so as to maintain your confidentiality until the time of your decision to participate. If you are interested in participating, you will consent to the release of your personal contact information by the MS Clinic to the student researcher, or will contact the student researcher directly.

The interview will be conducted and transcribed by the student researcher. The transcript will only be marked with an ID number. Your responses will be treated with utmost confidentiality. No personally identifying information about you will be given in the results of this research. Quotes or examples will be used from the transcribed interview data in the written report; however, names will be omitted and any other potentially identifying information will be changed. For example, personal pronouns (e.g., he, she) will be randomly assigned to protect the anonymity of the respondents or pseudonyms will be utilized. Only the researchers and the University of Calgary Conjoint Health Research Ethics Board will have access to participant information, so as to prevent unauthorized collection, use or disclosure of participants' personal information.

HOW WILL THE RESULTS BE USED?

Upon completion of the study, research findings will be available through The University of Lethbridge Library. The results may also be used in future presentations and/or publications. Hardcopies will be available to participants upon request and summaries will be sent to participating MS Clinics.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child's participation in the research project and agree to their participation as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw your child from the study at any time without jeopardizing their health care. If you have further questions concerning matters related to this research, please contact:

Dr. Jean Mah, MD, FRCPC (403) 943-7817

or

Dr. Kris Magnusson, PhD   Email: kris.magnusson@uleth.ca

or

Jennifer Thannhauser (403) 613-1399; jennifer.thannhauser@uleth.ca

If you have any questions concerning your child's rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782. Also, you may contact Rick Mrazek, Chair

Human Subject Committee, Faculty of Education, University of Lethbridge, at (403) 329-2452.

Parent/Guardian's Name   *Signature and Date*

Child's Name   *Signature and Date*

Investigator/Delegate's Name   *Signature and Date*

Witness' Name   *Signature and Date*

The investigator or a member of the research team will, as appropriate, explain to your child the research and his or her involvement. They will seek your child's ongoing cooperation throughout the study.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

The University of Lethbridge Department of Education Human Subject Committee has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

Appendix B

Information Letter

Dear MS Patient and Parent(s)/Guardian,

My name is Jennifer Thannhauser and, as a graduate student at the University of Lethbridge in the M.Ed. (Counselling) program, I am currently working on my thesis: which addresses the social experiences of individuals diagnosed with early-onset MS. The study will be supervised by Dr. Kris Magnusson, Ph. D., of The University of Lethbridge. Dr. Jean Mah and Dr. Jackie Bakker from the Children's Hospital and MS Clinic will also be involved.

The occurrence of early-onset MS is rare in comparison to the incidence rate among adults, nonetheless it is critical to understand the unique experiences of these individuals. Further, in order for the healthcare community to provide the most effective services for youth with MS, it is important for them to understand how MS can impact all areas of an individual's life.

The focus of the present study is on the peer relationships of individuals diagnosed with early-onset MS. The responses you provide will help others understand the relationships youth with MS have with their peers and how experiences within these relationships influence how they think and feel. Your participation is very important as only you can describe how your (your child's) MS impacts peer relationships: you are the expert.

Interviews will be arranged with the child/adolescent with MS and at least one parent/guardian. Your candid and thoughtful reply will help inform others of the experiences of youth with MS. It is anticipated that each interview will take approximately one hour. There will be separate interviews for the individual with MS and his/her parent/guardian. Your participation is completely voluntary and you are free to withdraw, without repercussions, at any point during the interview. The interview transcript will only be marked with an ID number. Your responses will be treated with utmost confidentiality. No identifying information about you will be given in the results of this research. Research findings will be available through The University of Lethbridge Library. The results may also be used in future presentations and/or publications. Hardcopies will be available to participants upon request and summaries will be sent to participating MS Clinics.

If you are interested in participating please contact me directly by email (jennifer.thannhauser@uleth.ca), or by calling (403) 613-1399, or inform your MS Clinic. If you have any questions or concerns, do not hesitate to contact me or my supervisor. You may contact my supervisor, Dr. Kris Magnusson, at kris.magunsson@uleth.ca. You may also contact the Chair of the Human Subject Research Committee, Rick Mrazek (403-329-2452 or mrazek@uleth.ca) if you have any ethical concerns about this study.

Sincerely,

Jennifer Thannhauser

Appendix C

Interview Protocol – Child/Adolescent Participant

Guiding Question	Theoretical Issue	Relevance	Question(s)	Process
Introduction		To develop comfort level.	1. Tell me about your diagnosis of MS.	1. Use of demographic sheet to ask for expansion/clarifica tion of diagnosis information.
			2. Outside of your family, who is in your world (i.e., who is really close to you, who might you hang around with sometimes but not always, who don't you associate with?).	2. Use of sociogram to explore who is in the individual's world (not including family); may prompt for close friends and peers if individual requires further clarification.
Social Support from Peers	Are friends/peers important sources of support? Do youth with MS have positive or negative social experiences with friends/peers?	To determine perceived importance of peers for support and the quality (e.g., positive experiences vs. negative experiences) of the relationships.	1. Based on this (sociogram), describe for me your experiences with the individual(s) in that network/group since your diagnoses: a) close friends; b) acquaintances; c) larger peer group	1. Probes and open questions will be used to get more depth out of the descriptions. The nature of the experience and the quality of the relationships will also be explored through follow-up probes.
			2. How important is this relationship to you?	2. Open question used to obtain their perception of the quality of this relationship.

Guiding Question	Theoretical Issue	Relevance	Question(s)	Process
Social Behaviours	Do the social behaviours of youth with MS impact their experiences with peers?	To identify social behaviours of youth with MS.	1. Have you noticed any differences with fitting in with your peers since your diagnosis?	1. Use open question follow-up to explore: i.e., If so, what have you noticed?
			2. Do you act the same way or differently?	2. Use open question follow-up to explore: i.e., How? What have you noticed?
			3. Do your friends act the same or differently?	3. Use open question follow-up to explore: i.e., How? What have you noticed?
			4. How do you react to your peers when they ask questions about your MS?	4. Follow-up with probes.
			5. How do you express your MS experiences to your peers?	5. Follow-up with probes.
Conclusion/ Wrap-up		To provide closure; ensure that all issues pertinent to participant are heard.	1. We've been talking about your experiences with peers since your diagnosis, what else would you like to mention that we haven't had a chance to discuss?	1. Use of open questions and probes to get clarification of story if new issues arise.

Appendix D

Interview Protocol – Parent Participant

Guiding Question	Theoretical Issue	Relevance	Actual Question(s)	Process
Introduction		To develop comfort level.	1. Tell me about your child's diagnosis of MS.	1. Use of demographic sheet to ask for expansion/clarificati on of diagnosis information.
			2. Outside of your family, who is in your child's world (i.e., who is really close to him/her, who might he/she hang around with sometimes but not always, who doesn't he/she associate with?).	2. Use of sociogram to explore who is in the child/adolescent's world (not including family); may prompt for close friends and peers if individual requires further clarification.
Social Support from Peers	Are friends/peers important sources of support? Do youth with MS have positive or negative social experiences with friends/peers?	To determine perceived importance of peers for support and the quality (e.g., positive experiences vs. negative experiences) of the relationships.	1. Based on this (sociogram), describe for me your child's experiences with the individual(s) in that network/group since his/her diagnoses: a) close friends; b) acquaintances; c) larger peer group	1. Probes and open questions will be used to get more depth out of the descriptions. The nature of the experience and the quality of the relationships will also be explored through follow-up probes.
			2. How important is this relationship to him/her?	2. Open question used to obtain their perception of the quality of this relationship.

Guiding Question	Theoretical Issue	Relevance	Actual Question(s)	Process
Social Behaviours	Do the social behaviours of youth with MS impact their experiences with peers?	To identify social behaviours of youth with MS.	1. Have you noticed any differences with your child fitting in with peers since his/her diagnosis?	1. Use open question follow-up to explore: i.e., If so, what have you noticed?
			2. Does he/she act the same way or differently?	2. Use open question follow-up to explore: i.e., How? What have you noticed?
			3. Does his/her friends act the same or differently?	3. Use open question follow-up to explore: i.e., How? What have you noticed?
			4. How does your child react to his/her peers when they ask questions about his/her MS?	4. Follow-up with probes.
			5. How does your child express his/her MS experiences to peers?	5. Follow-up with probes.
Conclusion/ Wrap-up		To provide closure; ensure that all issues pertinent to participant are heard.	1. We've been talking about your child's experiences with peers since his/her diagnosis, what else would you like to mention that we haven't had a chance to discuss?	1. Use of open questions and probes to get clarification of story if new issues arise.

Appendix E

Interview Probes and Prompts

1. So when you think of a scale of 1-10, where 1 doesn't disrupt you at all and 10 is the most disruptive and you can't function at all, where would you put yourself?
2. What do you mean by that?
3. Do you think that has anything to do with your experiences with MS?
4. In what way?
5. Can you give me an example?
6. How do they help you out?
7. How did you feel about that?
8. Can you think of some specific examples where you've had positive experiences with your friends?
9. Have there been any particularly negative experiences you've that you've had with anybody in regards to your experience with MS?
10. Any other changes like that since your diagnosis?
11. Does that impact your relationship with them?
12. How so?
13. Tell me about that.
14. What do you mean by...(reflect verbal content)?
15. Is this since you're diagnosis of MS?
16. Is that because of your MS?
17. Can you explain that?
18. Is that the same or different since before you were diagnosed?
19. Can you describe that a little bit for me?
20. What did that look like?
21. How has that changed your experience of MS?
22. Tell me a little bit about what it was like for you when you said....
23. Why do you think that happened?
24. How do you think that has impacted the quality of those relationships?
25. How was that for you when that was happening?
26. So, how would you describe that change then?
27. How did you feel when...?
28. What was that experience like for you?
29. How would you say that affected you emotionally?
30. Can you tell me more about that?
31. How else were they supportive?
32. What do you mean by that?
33. How did they react?
34. Like what?
35. How does that impact...(reflect verbal content)?
36. Tell me more about that.
37. And that makes you feel what?
38. How does that happen?
39. How do you make the decision to tell or not to tell about the MS?

40. Do you think they would?
41. Why would that be?
42. So what are your thoughts on that?
43. What did you think when that happened?
44. What was that like for you?
45. Can you tell me more about (reflect verbal content)?
46. Has anyone reacted that way?
47. So when you tell them, what would you say?
48. Do you think that impacts how your relationship is?
49. I was wondering if you knew what grief is?
50. I'm wondering if you've noticed (your child) going through any kind of grief process since the diagnosis?
51. What was that experience like for you?
52. Why's that?
53. And that made you...
54. How did they respond to that?
55. How might you (reflect verbal content)?
56. How much do you think the MS plays a role in that?
57. What was that experience like?
58. How do you think that impacted (your child)?
59. Why do you think that is?
60. Do you think the MS had anything to do with that?
61. Has that changed since (your child's) diagnosis?
62. In terms of?
63. How would you say that (reflect verbal content) plays out in the relationship?

Appendix F

Demographic Information Form

Gender:_____

Age:_____

Date of diagnosis:_____

Age at diagnosis:_____

Type of Multiple Sclerosis:_____

Date of first symptom(s):_____

Age at first symptom(s):_____

What were your first symptom(s)?_____

_____

Frequency of attacks:_____

Severity of symptom(s) based on your perception of how your symptoms disrupt your everyday

functioning: (Rate on scale of 1-10, where 10 is most severe, then describe)

_____

_____

_____

_____

Appendix G

Supplementary Interview Questions

1. Are there any additional losses, besides physical health, that you experienced?

2. Do your medications play a role in your peer relationships?

3. How are your experiences of MS impacted by your peer relationships?

4. How do you cope with others' responses to the MS?

5. What is your understanding of grief?

6. Does grief play a role in peer relationships?