



**Multiple Sclerosis  
Society of Canada**

# **GROWING UP STRONG: SUPPORTING THE CHILDREN OF PARENTS WITH MS**

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## **LITERATURE REVIEW**

### **CONTENT:**

|    |  |    |
|----|--|----|
| 1. | SUMMARY.....   | 2  |
| 2. | BACKGROUND.....  | 3  |
| 3. | LITERATURE.....  | 4  |
| 4. | FINDINGS .....   | 5  |
|    | 4.1 Are there relevant resources on the needs of children of parents with MS?<br>What is known about the needs of children of parents with MS? ..... | 5  |
|    | 4.2 How do parents assess the impact of MS on their children’s lives? .....  | 6  |
|    | 4.3 How do children perceive and cope with their parents’ disease? .....   | 8  |
|    | 4.4 What are the emotional issues faced by the children of parents with MS? .....  | 10 |
|    | 4.5 What are the social issues faced by the children of parents with MS? .....   | 11 |
|    | 4.6 What are the physical issues faced by the children of parents with MS? .....   | 14 |
|    | 4.7 What are the educational issues faced by the children of parents with MS? .....  | 14 |
|    | 4.8 Recommended approaches and tools for the healthy development of<br>children of parents with MS.....  | 16 |
| 5. | CONCLUSIONS .....  | 17 |
| 6. | ACKNOWLEDGEMENTS.....  | 18 |
| 7. | REFERENCES .....   | 18 |

## 1. SUMMARY

The present literature review is an early milestone of “*Growing Up Strong: Supporting the Children of Parents with Multiple Sclerosis*”, a 2-year national project funded by Population Health Fund of Health Canada and coordinated by the National Client Services department of the MS Society of Canada.

The core objective of this literature review is to help us build a strong knowledge base regarding the educational, emotional, social, and physical needs of children of parents with multiple sclerosis. This knowledge base will be applied to a number of future steps of the project.

The present literature review summarizes 26 documents, including: one monograph (identified by NMSS as one of the best sources of information on the topic), eight studies, two papers, one literature review, four journal articles, seven popular articles, and three books.

The findings of this literature review show a unanimous conclusion that more research is needed about the children of parents with MS, a population that has been labelled “at risk”. Existing literature shows that parents with MS are concerned about the effect of their illness on their children, however they tend to minimize the negative effects of MS on their children’s lives and development and maximize the positive ones, while children report more coping difficulties than their parents report them as having. Some children may be emotionally affected by MS within the family, while others may not show apparent ill effects. Child’s age and gender, and parent’s MS symptoms are some of the factors that influence the effect of MS on children’s lives. As a result of parental MS, children may face significant emotional needs and their social life may be disrupted: family lifestyle, school life and time with friends might be affected. Children’s caregiving responsibilities have a significant impact, with both negative and positive aspects, on a child’s normal development into adulthood. Studies agree that most children show a lack of understanding regarding MS due to poor education in this field which may translate into reinforced preconceptions of an illness such as fear that their parent may die, they may get the disease or pass it to their children.

In conclusion, there is evidence that children of parents with MS will have a healthy and stable development and the negative impact of MS can be significantly reduced with the support of special resources and programmes that address their unique needs. Resources and programmes for parents and health care professionals should be considered as part of supporting the healthy development of children of parents with MS.

## **2. BACKGROUND**

The present literature review is an early milestone of “*Growing Up Strong: Supporting the Children of Parents with Multiple Sclerosis*”, a 2-year national project funded by Population Health Fund of Health Canada and coordinated by the National Client Services department of the MS Society of Canada. *Growing up Strong* was launched in August 2002.

Given the positive response to pilot programs and services that have been offered to date and believing that the health needs of children of parents with MS are far greater than the average population the project will develop, evaluate and deliver integrated services and programs nationwide for children aged 6-18 who have a parent or parents with MS. These programs and services would address the unique educational, emotional, social, and physical needs of children of parents with MS. This process would take place in the context of ongoing evaluation of outcomes in relationship to population health objectives.

The core objective of this literature review is to help us build a strong knowledge base regarding the educational, emotional, social, and physical needs of children of parents with multiple sclerosis. This knowledge base will be applied to a number of future steps of the project including:

- Needs assessment;
- Gap analysis;
- Establishing evaluative criteria and outcome indicators; and
- Developing resources to pilot new programs and services to address the needs of children of parents with MS.

The findings of this literature review will be further applied in connection with other Society activities related to the quality of life and multiple sclerosis.

To reach this objective we have:

- Identified sources of information;
- Gathered relevant materials;
- Synthesized the results into a summary of what is and isn't known regarding the needs of children of parents with MS; and
- Evaluated the findings by identifying literature discrepancies and developing questions for further research.

### **3. LITERATURE**

The present literature review summarizes 26 documents that were identified by the project team, including:

- 1 monograph (identified by NMSS as one of the best sources of information on the topic),
- 8 studies,
- 2 papers,
- 1 literature review,
- 4 journal articles,
- 7 popular articles, and
- 3 books.

As it became obvious in the very beginning of the data collection process that there is not a high volume of resource materials dedicated to MS and the effect it has on children of parents with MS, we extended our research to materials on chronic diseases and disabilities in general. Therefore, 5 out of the 26 resource materials do not refer specifically to MS, but to chronic diseases (3 documents) and disabilities (2 documents).

The resources were identified with support from the experts with:

- **The National Information Resource Centre** of the MS Society of Canada, using the following tools:
  - ✓ **ASK MS**, a comprehensive internal database containing a wide spectrum of print material on multiple sclerosis, from research and scientific papers to books and articles written by persons with MS.
  - ✓ **Medline**, an index of international biomedical journals published by the National Library of Medicine (US), offering summaries of scientific articles.
  - ✓ **Internet** research for the latest medical information and news. Keywords used included: children, chronic disease, disability, family, family relations, multiple sclerosis, and parent/child relationship.
  - ✓ **University of Toronto Library** research for specific materials identified using the above-mentioned tools.
- **The Professional Resource Center** of the US National Multiple Sclerosis Society.
  - ✓ This Resource Centre has the most comprehensive MS library in the world comprising over 11,000 journal articles from 1938 forward, 1,200 books on MS and 137 subscriptions.

## 4. FINDINGS

In this chapter we focus on identifying the issues and needs of children of parents with MS. In addition to that, in the course of our research it became apparent that there is insufficient research conducted in the field, which may affect the outcome of this process. Therefore, we considered it was necessary to include in our findings a separate section analysing the existing research and the need for further research, which opens this chapter.

The complete list of resource materials covered by this literature review is included in Chapter 7 herein. *Note: All items were numbered and their respective numeric references are included between brackets in the findings below.*

### **4.1 Are there relevant resources on the needs of children of parents with MS? What is known about the needs of children of parents with MS?**

Nearly a decade ago, the acute lack of resources in Canada for children of parents with MS became a documented issue. All the materials reviewed agree on the fact that the research needs in this area remain largely unaddressed and that there is little conclusive research on this population of children (2, 6, 22, 23). The unanimous conclusion is that more research is needed about the children of parents with MS, a population that has been labelled “at risk”.

A significant part of the existing literature focuses on ill children and their parents and very few studies were conducted on children of chronically ill parents (6). The majority of research on disability is about either children or male adults with disabilities (23).

Some of the studies included in the current literature review focus on the effect of MS on children of parents with multiple sclerosis, others focus on children of parents with chronic illnesses (including MS), disabilities (referencing MS) or terminal diseases. Because there are so few resources, many of them reference the same material or materials and this may have impact on its overall outcome and on the citations in the literature review.

Another factor that needs to be taken into consideration is that the existing studies present several limitations, such as:

1. Most of the studies were conducted on subjects who were recruited from the membership of local MS chapters. Therefore the findings cannot be generalized to the MS population as a whole. However, they can be generalized with some confidence to the subpopulation from which they are drawn – those individuals and families living with MS who choose to affiliate themselves with the MS Society (1).
2. The financial constraints forced most of the projects to focus on a relatively small number of subjects who may vary significantly in terms of their demographic characteristics, disability status, and illness history (1).

3. The early studies (25; Arnaud, 1957), suggesting that being reared by a parent who has MS is detrimental for the child, rely on children who were identified from among active patients in medical environments. Persons actively involved in medical environments that focus on the illness aspects may be different from persons with MS who were identified through community support programs that focus on living with MS (23).
4. Limited and poorly controlled research designs have been used to describe parent-child interaction when a parent has a chronic illness. Methodologies that fail to control the bias include: case studies that attribute a child's clinical pathology to disability, retrospective surveys and poor classification and control of the illness variable. Research on parent-child dyads in which parents have no disabilities may not be able to be generalized to atypical parenting situations (23).

One study including a review of the existing research on parenting and disability in general and MS in particular (23) concludes that one of the problems in the literature on parents with disabilities or chronic illness has been the overgeneralization of research outcomes to inappropriate situations, especially in legal and social policy environments.

#### **4.2 How do parents assess the impact of MS on their children's lives?**

Because MS so often begins in young adults just when they are beginning their family, parents with MS are especially concerned about the effect of their illness on their children, as all must live with the uncertainty of MS and its course.

There is agreement among most parents that their children are coping relatively well with the stress of MS in their lives. However, parents tend to minimize the negative effects on their children's lives and development and maximize the positive ones, while children report more coping difficulties than their parents report them as having. In Batten and Gardner's (1993) survey of 313 parents of children eighteen and under, only the most severely disabled parents felt that their children were experiencing serious difficulties (1).

Interviews with parents and children show that the adults tend to underestimate the emotional impact of MS on their children's lives, and the children reported more coping difficulties than their parents described them as having. The children were having much greater difficulty with the parent's mood changes and the emotional climate of anxiety, sadness, and tension within the household. Many of the children felt that they were unfairly targeted by their parent's anger and frustration, and described a "walking on eggshells" atmosphere in the home. Some children hesitated to ask their parent MS-related questions for fear of upsetting the parent (21).

Although parents tend to underestimate the emotional impact of MS and its physical symptoms on their children (1, 11), other materials show that one of the major concerns for parents is the effect that their illness may have on their children (2, 22).

The studies identify significant divergences between the parents' and children's perceptions of MS. Adult children describe their parents as more disabled than the parents describe themselves

(1, 11). The children of severely disabled parents describe their own adult lives as having more difficulties than their parents described them as having (1).

MS treatment goals should focus on lifelong living with a disability and should support a variety of social roles to ensure quality of life. One of these important and highly valued roles is being a parent. The disability, the emotional response to the disability, or community attitudinal barriers may exacerbate the stress inherent in everyday living and alter the performance of life roles, thus resulting in possible deterioration of parenting functions (23).

Parents fear that the illness will prevent them from being a ‘good parent’. By providing parents with tools and techniques to make MS part of their daily lives and better cope with the illness, children will be enabled to enjoy a better quality of life. This is the conclusion of several anecdotal articles, parent testimonies, and real-life parenting tips referenced in this review. Knowledge of the effect of MS on children in the family is a critical ingredient in decreasing its negative impact (7). Another common parent’s worry is meeting children’s financial needs. Parents also express guilt about children being under pressure and about the need to ask for help with housekeeping chores (6).

Parents need to be reassured that the effects of their MS will not necessarily cause psychological problems for their teenagers: most adolescents are proud of their parents with MS and often grow up to be more sensitive than their peers to the needs of others and to be more self-reliant.

Parents need to get used to the idea that they need outside help (1) as they generally believe that their children do not need “professional support” to cope with parental MS (1, 11, 21). Anecdotal articles encourage parents to contact a social worker / youth counsellor if they need advice on how their children cope with the parent’s disease. Some parents acknowledge the needs of their children and have launched calls for pen pals and children support groups (19).

The materials reviewed acknowledged the necessity of information about parenting with MS. A parent with MS recommended that relevant information should be available to health professionals so they can help newly diagnosed parents to parent in a way that enhances their lives and the lives of their children (16). Mothers with MS expressed their need for information on resources about how to engage more fully in roles outside the home with parents without disabilities, friends, workers, and so on (23).

Learning from other parents’ experience might be a good solution (17). In fact, two mothers reported that when they discussed their current parenting problems and fears with mothers without disabilities, their current concerns were the same as those of the other mothers. One mother said that through these typical social contacts she realises that her concerns are part of the normal parenting processes (23).

Although there are fairly typical problems that MS can present for parenting, it is important to recognize that there are marked individual differences in family strengths, coping styles, and social and emotional resources. Some individuals and family characteristics seem to be related to better coping and adjustment to MS, including flexible problem-solving skills, a strong social support network, and the willingness to seek and accept help as needed.

### **4.3 How do children perceive and cope with their parents' disease?**

#### *General considerations*

Most studies identify children who have a chronically ill parent including MS as “at risk” in psychological and social domains (6,7, 8, 12). It is known that children of parents with chronic diseases such as MS experience a unique lifestyle and challenges far greater than children of well parents. The stresses related to adapting to the unstable, progressive, disabling conditions associated with MS might be overwhelming for affected parents and their children (23).

More recent research on parents with a disability or chronic illness has not demonstrated negative outcomes for children reared in this unique situation. (Buck & Hohmann, 1983; Maybury & Brewin, 1984; Crist, 1992). However, early research has contradicted these findings (Arnaud, 1959; Frank, 1978; Olgas, 1974). Perhaps the later results reflect the effects of contemporary attitudes toward parents with disabilities or illnesses, which are less stigmatizing, more supportive and less negative than the predicted attitudes in earlier studies (23).

The conclusion is that some children are emotionally affected by MS within the family, while others do not show apparent ill effects. It is a mistake to ignore the emotional concerns of children of parents with MS but at the same time one should not jump to the conclusion that such children are invariably psychologically troubled.

#### *Age*

There are age specific differences in the effect of the disease on children of parents with MS. It is important to remember that a child's developmental level influences what he or she can understand about the parent's illness (21):

- Children under 6 are less likely to be affected (11).
- For children between 6-12 problems may arise as the child attempts to comfortably integrate into the larger society, with issues such as shame and embarrassment at the forefront (11).
- Most adolescents in MS families appear to be psychologically healthy; they do not differ from control group adolescents in mood, body image, social, academic functioning or relationship satisfaction with their parents. However they worry significantly more than their peers about their parents' health, they feel uneducated about MS, only a few speak to professionals to express their concerns and get help when needed. Adolescents care about parent's deteriorating health, stressful effects on well parent, reduction of family income and activities, and unpredictability of behavioural changes (5).

### *Gender*

Gender seems to be an important moderating factor in chronic parental disease and it has complex effects on the coping capacity of children. The gender of the child significantly influences his or her coping behaviour: daughters cope better than sons, independently of the gender of the MS-affected parent; healthy mothers and daughters cope better with the increasing disability of the father. This is not the case for healthy fathers and sons (3). However, other research concludes that males appear to be more adversely influenced than females (8).

### *Effects of MS symptoms*

There are acute differences between the mothers' behaviours between exacerbation and non-exacerbation times in terms of physical nurturance. Mothers significantly underestimate changes in their physical affection. Yet the 6-to-20-year olds appear to be confused by the unpredictability of the behaviour changes because they had been given very little explanation of the illness. Children may or may not understand why their mothers enjoy physical contact one day but not the next, as the sensory changes that occur during an exacerbation of symptoms may make physical contact painful (1, 24).

Less visible MS symptoms such as fatigue and psychological changes seem to have as great an impact on children as more visible physical changes, but are acknowledged and talked about less frequently by parents (1).

The effect of the mother's severe clinical depression on the children has been studied by Cohler and Musick (1982) who found that such children showed a severe developmental deficit. Depressed mothers were observed to be emotionally unavailable to their children and unable to meet the children's needs (8).

As one parent with MS testified, "kids can handle the physical changes. They can handle a parent who needs mobility aids to walk. They just want a parent who can share time and activities with them and be there for them emotionally" (14).

### *Other findings*

A study found that children of parents with MS reported greater family conflict and less family cohesiveness, organization and intellectual-cultural orientation than matched children.

Most of the children appear to be empathetic to the parent with a disability (12). Children of parents with MS appear to have a high degree of sensitivity to others, particularly to disabled persons. They develop empathic skills and the ability to see the world from another's perspective and show higher potential for mature friendship relations. Other effects include: acceptance, humour, character admiration and genuineness (6, 8).

Children expressed their need for open communication. They need to feel they can ask questions and voice concerns at any time. This can give them a sense of stability and consistency, despite the ups and downs of the disease (14).

#### **4.4 What are the emotional issues faced by the children of parents with MS?**

“Typical” childhood challenges often become far more daunting when a parent has MS. For example, separation anxiety is particularly common in younger children when they begin to attend school. They may worry that something bad will happen to the MS parent while they are gone, or that the parent will need help and will not have anyone to provide it. Talking openly with children about MS helps relieve their anxiety (21).

Certain MS-specific events, such as a parent’s hospitalization with an acute exacerbation, cause children to feel especially vulnerable. Children experience increased anxiety during these periods of separation from their parent. Children typically see hospitals as places for the very sick or the dying. Children, particularly those of single parents, dislike the prospect of being cared for by someone else while the parent is away. The anticipated and actual disruption of their daily routine as a result of the parent’s absence is a major source of unhealthy anxiety.

Children in single-parent families are at increased risk, having already felt the loss of one parent from the home.

Children fear their parent’s death (7, 12) and they need constant reassurance (15).

Early studies (Arnaud, 1957; Frank, 1978; Olgas 1974) describe children of parents with MS as constrained, depressed, antisocial, hostile, with heightened levels of dysphoria (unhappy, sad feelings), with bodily concerns, constrained interpersonal relationships, dependency longings, and a false or precocious maturity (2, 6). Children may assume an adult role as a caregiver that may lead to pseudo-maturity (11).

Some studies conclude that children who have a parent with a disability often display negative behaviours. These behaviours include jealousy, increased competitiveness and sibling rivalry, anger, hostility, social withdrawal, attention-seeking behaviours and a decline in academic performance. Children who have a parent with disabilities long for love and recognition in their own right. When approached by others, children are frequently asked: “How is your mother/father doing?” instead of “How are you doing?” (12).

However, recent research on parents with a disability or chronic illness (Buck & Hohmann, 1983; Maybury & Brewin, 1984) has not demonstrated negative outcomes for their children (23).

Children of parents with MS seem to be more caring and sensitive to the needs of the disabled (1), more empathetic and advanced in friendship concept development than the general population (2, 6). Parents with MS report a number of benefits of their children have experienced including: increased thoughtfulness as children mature into an independent and resourceful person, with positive power of honest communication, compassionate, sensitive to the hardships of others. Parents testify that MS aided the child as he was confronted by his own significant life challenges (18).

### *Dealing with parent's issues*

Children can deal with the physical limitations and changes. They can understand things they see (1, 14). This is why children sometimes interpret the parent's high fatigue level often as laziness and cannot understand moods: parental yelling, crying, mood swings, irritability are perceived as common and upsetting events in the household (1). Children face major difficulties in coping with cognitive impairment (1, 14).

Less visibly obvious symptoms can have as great an impact on children as the more obvious ones, but are less often talked about by both parents and researchers (1).

Parentification of the child is another issue, that is, the process by which a child prematurely assumes the responsibilities of the parental role. These children become increasingly sensitive, they have nurturing abilities, they become increasingly cooperative, and according to some empirical data, they demonstrate an increase in self-esteem and cognitive mastery. Although parentification is sometimes seen as a positive, it is not always desirable. In this process, some children lack the nurturing they should receive from the parent and they may miss the normal developmental phases of childhood (12).

## **4.5 What are the social issues faced by the children of parents with MS?**

The ability of children reared by parents with a chronic illness to move successfully into adult roles and behaviours is the essence of social concern (23).

It is not unusual for children who have an ill parent to assume responsibilities far beyond their years. Many children who have a parent with MS are assigned more than the usual number of chores around the house. More serious problems can result when school age and adolescent children become the sole caregivers for their parents because of a lack of community services and the unavailability of other adults to provide care. In these situations, the kinds of physical contact that are required for personal care activities like bathing and bowel and bladder care often cause significant discomfort for both the child and the parent. In addition to their emotional distress, children who have such responsibilities may be absent from school often enough to interfere with their schoolwork and cause them to miss out on other important age-appropriate activities.

In some families, children may begin to take on so many additional responsibilities that they function as a co-parent for siblings. A young woman reported: "I have a brother who called me mother for about a year because he didn't know otherwise...I was about 14 at the time" (4).

Although these children may initially enjoy their newfound sense of authority and special position, they are likely to become quite confused about their role in the family, particularly if they still need nurturance and supervision themselves. They are also likely to resent the interference of these extra responsibilities with their own activities.

According to adults' recollections of their experience as young caregivers of family members with chronic physical illness, the areas most likely to be affected by caregiving included family life, school and time spent with friends. These adults identified personal care (feeding, bathing, dressing) as the most difficult of the caregiving tasks, and household chores as the most time consuming ones (4).

#### *Effects on family lifestyle*

When a parent becomes ill, the family is disrupted. Disruptions to the family may include sudden limits, or even great reductions, in financial resources, which may deprive the children of material possessions and the opportunity for recreational experiences (12).

Roles of all members within families of these children undergo frequent changes as the parent's capacity to perform previous functions fluctuates in remissions and exacerbations (6). Frequent changes in residence may occur to a less expensive or more physically accessible one, as well as a drain of financial resources that leaves the family with less (6).

Prescribed dietary changes may influence family meals (6, 8).

#### *Children in a caregiving role*

The daily time spent with caregiving activities increases significantly when a parent has MS (4). As children take the responsibilities of the caregiver, the normality of childhood is lost. These children can have feelings of isolation, egocentricity, inferiority, or inadequate knowledge about some aspect of their parent's condition (12).

Children tend to be required to fulfill many of the household chores that had been previously the responsibility of the ill parent. Increased responsibilities and chores allow less time for children's recreation (6).

Below are listed some of the caregiving activities in which children of parents with MS were involved:

- *Personal care activities*, especially of a more intimate nature, and especially if the parent was the opposite gender, were the least likely to be given to youngsters. In almost all cases, the child was not the only member of the family involved with caregiving (4, 10).
- *Medical care* was perceived as the least time consuming, yet more information was required about what they were doing.
- *Household care* (preparing meals, babysitting, cleaning, laundry) was seen as the most time consuming.
- *Spending time with the ill person* (visiting, praying, playing games, reading)
- *Other tasks* include: gardening, paying bills, and "self care – things mom would normally do for me I had to do for myself" (4).

"Children should be allowed to be a caregiver, not forced and not full time," says a mother who was a caregiver as a child (6).

### *Effects on school life*

Adults who had parents with MS recollect that there was a pronounced effect on school life. They report less time for homework and extra-curricular activities, which increased as they progressed in school. “Missing classes and special events” became more upsetting in the high school years. Some report they dropped out of school because of increased caregiving responsibilities (4).

There are divergent opinions regarding the effect of caregiving on school life. Some studies show reduced school performance and antisocial behaviour (8). The children can have a difficult time focusing their attention and concentration on daily activities (12). Other children did fine with school, reporting that the ill person would spend time helping them with homework and would encourage them (4).

School may give children “a break” from the responsibilities at home. “School was different from the horror at home”, reports a young adult who was a caregiver as a child (4).

Children can follow their academic and social routines more comfortably when they are reassured that the parent wants them to pursue these activities, knows how to take care of himself or herself, and has resources to call upon if help is needed (21).

### *Effects on social life*

Formal and informal labelling of family members contributes to social isolation of some of the families where a member has MS (6, 8).

Some children of parents with MS are embarrassed by the parent’s disabilities, which may affect their social life.

Friends are reported as being very important. Although peers are a viable and important source of social support for these children, the anxiety of ill parents may limit the character of their children’s peer relations (8). Children may dislike speaking to peers whose lives have not changed. Most of the children seem to believe that other children lack an understanding of their situations, because their friends’ families continue to go through life as they did prior to the illness that has so deeply affected their lives (12). Frequent relocations and reduced financial resources meant that friendships were difficult to maintain (6).

There is a dichotomy in responses: for some, parental MS did not affect friendships, friends “understood”, “helped me with care” and were “supportive”. Some reported fewer friends because of having less time for them or being reluctant to tell friends of the caregiving responsibilities (4).

The children who were dating age either did not date or dated early “to get out of home”, especially in those situations where caregiving occurred over a prolonged period. One woman reported that she “married the first person I dated to escape” (4).

#### **4.6 What are the physical issues faced by the children of parents with MS?**

The materials covered by this literature review do not address the physical effects of parental MS on children, except for the increased caregiving role that may result in a series of physical activities exceeding the children's physical abilities.

No other physical effects were studied, such as: sleep deprivation, nutritional imbalances and others, and may require further research.

#### **4.7 What are the educational issues faced by the children of parents with MS?**

A child's educational level and needs dramatically influence what he or she can understand about a parent's illness.

For example, a young child might believe that his father's brace is in place because his leg was broken in a fall witnessed the week before, and it will come off again as soon as his leg heals. Adolescents, however, are able to think about things in more complex and abstract terms, and require far more sophistication in understanding their parents' MS and its impact on their own health.

##### *Lack of understanding of MS*

Studies agree that most children show a lack of understanding regarding MS due to poor education in this field. Young children and adolescents are very accurate observers of their parents' physical and emotional states but demonstrate surprisingly little accurate knowledge about MS.

Possible causes include: the complexity of the illness, parental inability to discuss or explain it, parental unwillingness to talk about the illness or its symptoms, children's developmental limitations in understanding the available information, coping strategies that reduced or simplified the available information, and limitations of available MS related educational programmes for children (1, 10).

##### *Effects of lack of information*

Children often have their own preconceptions of an illness that may be reinforced if they're left in the dark (20). Thus, some children believe MS is contagious, it is directly transmitted genetically, or arrives by fate (1, 6, 7, 10, 11). Older children and adolescents tend to be concerned about getting MS themselves or passing it to their own children; younger children want to know if people can 'catch' MS and if their parent will die (21).

Certain studies conclude that children do not have the capacity of pessimism about the future thus they don't believe the parent's MS may get worse (1).

The lack of information may also result in guilt feelings. Some children believe that their own behaviour affected the course of their parents' MS, or other people's behaviour toward the parent affected the MS (1, 11). Adolescents feel guilty for leaving their ill parent (6). They need to be able to explain their parents' MS to peers, to avoid feelings of embarrassment and isolation. Educating children should be an ongoing process (5, 10).

### *Need for information*

There are discrepancies between what parents think and what children think in terms of information needs. Parents seem to feel that children should be told about MS on an as-needed basis, when the symptoms become more visible and/or debilitating. In contrast, adult children think that even young children should be given all available information about a parent's illness (1, 11).

"Not answering questions honestly can lead a child to feel isolated and afraid," says a mother from Nova Scotia (20). Adult recollections of their childhood with parents with MS underline that it is imperative that youngsters be told what is going on with ill adult (4).

Children should be provided with an opportunity to ask questions about MS (7).

### *Age appropriate information*

Children will have the greatest difficulty understanding symptoms they cannot see (21). If it's very concrete, young children can understand that. They want to know what is going on. An older child may require considerably more detail than a young one (20).

When talking to a child about MS symptoms, it is often useful to describe and demonstrate the symptoms in a fairly concrete way that they can more easily understand. MS fatigue could be described as the feeling that they would get if they tried to walk around with weights on their arms and legs. Vision problems might be described as feeling like one is looking through a mesh screen all the time or looking at a movie screen with a big hole in the middle. The feeling of spasticity may be illustrated by letting children try walking with an elastic bandage around each leg. Children could experiment with assistive devices like canes, crutches, a motorized scooter or a wheelchair (21).

In addition to their developmental differences, children often have personal preferences about the kind and amount of information they want about MS, the form in which it is conveyed and who should provide the information. Some children may want to read the information on their own, ask questions as they come up, whereas others may prefer to accompany their parent to MS related appointments where they can direct questions to members of the healthcare team (21).

#### **4.8 Recommended approaches and tools for the healthy development of children of parents with MS**

Many materials covered by this literature review included recommendations derived either from research or based on real-life experience, including:

- Supportive and educational groups with families, with ill parents and with children of ill parents can contribute toward positive adaptation of children to their parent's illness.
- Providing the children with the opportunity to share their grief, rage and fears will result in less denial problems.
- Teaching of health-related issues will reduce fears about issues such as heredity, disability, and death.
- Information should be shared with the family as a whole, and should not exclude children from learning more about a reality that has great importance for the whole family.
- Discussion in a group of similar-aged children who have a parent / parents with MS may provide a means to ventilate feelings and gain health education; such a group can create solutions to problems raised by any member of the family.
- Parenting focus groups aimed at building communication skills may contribute to enhancing confidence and skills in parenting and reduce fears related to family adjustment to illness.
- Providing children with opportunities for respite from caregiving activities.
- Providing information sources, teaching children about MS, and providing opportunities for children to meet with children who share their experience can contribute to the child's normal development and adaptation to the parent's MS.
- Providing outside caregiving services.
- Early intervention by nurses is found as essential. Nurses can encourage communication, promote effective parent-child interactions, decrease children's fears, and foster positive attitudes about disabilities.

## **5. CONCLUSIONS**

1. There is limited research addressing the needs of children of parents with MS, therefore it is difficult to draw pertinent conclusions regarding children's needs solely relying on the existing research.
2. Children of parents with MS appear to be at higher risk for emotional, educational, and social difficulties than children of healthy parents, according to available research.
3. The issues of the children of parents with MS are complex; they face more difficult problems than most of the children and therefore have a different lifestyle than the other children. They experience emotional, educational, social and even physical challenges.

In conclusion, among others, children of parents with MS need:

- To be told what is going on.
  - To have their questions answered.
  - To know that nothing they did caused MS.
  - To be allowed to grieve.
  - To talk about the disease with someone outside the family if this makes him or her more comfortable.
  - To know it's OK to feel angry because their lives have changed.
  - To be reassured that their actions do not control the parent's illness.
  - To be allowed to remain an active part of their parent's lives.
  - To be encouraged to show their emotions, which prevent them from 'bottling' things up in a misguided attempt to 'protect' the ill parent.
4. With the support of special resources and programmes that address the unique needs of this category of children there is evidence that they will develop to be healthy and stable, and the negative impact of MS can be significantly reduced. Such tools need to be multi-age, multi-level (parent's mild-severe MS) and multi-media.
  5. Since the family has a pivotal role in the children's healthy growing and the parents tend to underestimate the effects of MS on their children, resources and programmes addressing the parenting issues should also be developed.
  6. A special consideration should be given to health care professionals as they play a major role in identifying the problems and may guide the parents with MS and their children through a variety of support programmes and resources.

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## 7. REFERENCES

- 1 Kalb, Rosalind C. *Families Affected by Multiple Sclerosis: Disease Impacts and Coping Strategies*, Health Services Research, National Multiple Sclerosis Society, 1995.
- 2 Lino-Kilpi, Helena; Luoto, Eija; Katajisto, Jouko *Elements of Empowerment and MS Patients* in *Journal of Neuroscience Nursing*, Volume 30, Number 2, 1998, pp. 116-123.
- 3 Steck, B.; Amsler, F.; Kappos, L.; Bürgin, D. *Gender-Specific Differences in the Process of Coping in Families with a Parent Affected by a Chronic Somatic Disease (e.g. Multiple Sclerosis)* in *Psychopathology* Volume 34, Number 5, 2001, pp. 236-244.
- 4 Lackey, Nancy R.; Gates, Marie F. *Adults' Recollections of Their Experiences as Young Caregivers of Family Members with Chronic Physical Illnesses* in *Journal of Advanced Nursing*, Volume 34, Issue 3, 2001, pp. 320-328.
- 5 *Psychological Issues Among Adolescents in Families Which a Parent has Multiple Sclerosis – Health Care Delivery & Policy Research Results* Information note in *Research & Medical Programs Department News* of National Multiple Sclerosis Society, Jan. 1996.
- 6 Blackford, Karen A. *Strategies for Interventions and Research with Children or Adolescents Who Have a Parent with Multiple Sclerosis* in *Axon*, 1992, pp. 50-54.
- 7 White, David M.; Catanzaro Marci L.; Kraft George H. *An Approach to the Psychological Aspects of Multiple Sclerosis: A Coping Guide for Healthcare Providers and Families* in *Journal of Neurological Rehabilitation* Volume 7, Number 2, 1993, pp. 43-52.
- 8 Friedmann, Marie-Luise; Tubergen, Polly *Multiple Sclerosis and the Family* in *Archives of Psychiatric Nursing*, Volume 1, Number 1, Feb. 1987, pp. 47-54.
- 9 Blackford, Karen A. *The Children of Chronically Ill Parents* in *Journal of Psychosocial Nursing*, Volume 23, Number 3, 1988, pp. 33-36.
- 10 White, David M. *Treating the Family with Multiple Sclerosis*, in *Physical Medicine and Rehabilitation Clinics of North America*, Volume 9, Number 3, 1998, pp. 675-687.
- 11 Tainsky, A. *How to help Kids Cope with a Parent's MS* in *Real Living with Multiple Sclerosis*, Volume 2, Number 8, 1995
- 12 Flickinger, Edith E.; Amato, Shelly C. *School-Age Children's Responses to Parents with Disabilities* in *Rehabilitation Nursing* Volume 19, Number 4, 1994, pp. 203-206.

- 13 Tofteland, Marcia T. *From Embarrassed to Educator in Real Living with Multiple Sclerosis* Volume 9, Number 6, 2002, pp. 8-9.
- 14 Savage, Kathleen *Fathers with MS – Parenting in a Different Package* in Real Living with Multiple Sclerosis, Volume 4, Number 2, 1997, pp. 8-10.
- 15 Peterman-Schwarz, Shelley *A Crash Course In Being a Mom... With MS* in Inside MS, Spring Issue, 1991, pp. 24-33.
- 16 Belehorec, Anne; Kikuchi, June F. *How do you mother when you are disabled?* in The Canadian Nurse, March issue, 1985, pp 32-35.
- 17 Peterman-Schwarz, Shelley; Pollina, Stacy; English, Jennifer; Horn, Valerie *A time to weep and a time to laugh: kids, parents & MS*, Inside MS, Summer Issue, 1991, pp. 21-25.
- 18 Tofteland, Marcia T. *A Child in the House of Love* in Real Living with Multiple Sclerosis, Volume 9, Number 4, 2002, pp. 6-7.
- 19 Elliston, Sheryl, *Pen pals for children of parents with MS* in MS Ontario, November issue, 1993, pp. 5.
- 20 Reynolds, Lindor *Why is mommy Sick? The Critically-Ill Parent* in Today's Parent, May issue, 1993, pp. 31-35.
- 21 Crawford, P.; Miller D. *Parenting issues* in R.C. Kalb (Ed.) *Multiple Sclerosis: A Guide for Families*, Medical Demos Publishing, New York, 1998, pp. 78-83.
- 22 *Multiple Sclerosis: Current Status and Strategies for the Future*, Institute of Medicine, National Academy Press, Washington DC, 2000, pp 204-207.
- 23 Crist, Patricia *Contingent Interaction During Work and Play Tasks for Mothers With Multiple Sclerosis and Their Daughters* in The American Journal for Occupational Therapy, Volume 47, Number 2, 1993, pp. 121-131.
- 24 Deatrick, Janet A.; Brennan, Daniel; Cameron, Mary Emily *Mothers with Multiple Sclerosis and Their Children: Effects of Fatigue and Exacerbations on Maternal Support* in Nursing Research, Volume 47, Number 4, 1998, pp. 205-210.
- 25 Olgas, Marya *The Relationship Between Parents' Health Status and Body Image of Their Children* in Nursing Research, Volume 23, Number 4, 1974, pp. 319-323.
- 26 McCue, Kathleen; Bonn, Ron *How to Help Children Through a Parent's Serious Illness*, St. Martin's Press, New York, 1994.