

Emotional and Behavioral Encounters of Children with Parental Multiple Sclerosis

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### Abstract

Multiple Sclerosis (MS) is a demyelinating disease of the central nervous system and is prevalent among adults who have school-age children. Persons diagnosed with MS often experience physical and psychological disabilities that are likely to affect the health of children, other family members, and their caregivers. Children whose parents have MS are at a higher risk for experiencing socioemotional and behavioral issues when compared to their counterparts (Armistead, Klein & Forehand, 1995; Bjorgvinsdottir & Halldorsdottir, 2014; Razaz, Nourian, Marrie & Tremlett, 2014), and have often been labeled as “at risk”. The socioemotional and behavioral risks incurred by these children have interfered with their school attendance, performance, and academic success, exemplifying the need for early interventions that prevent and mitigate associated challenges. Therefore, this paper will: (a) discuss literature pertaining to Multiple Sclerosis and the impact it has on their children, (b) review behavioral and socio-emotional challenges of children whose parents have Multiple Sclerosis, and (c) provide counseling strategies and effective interventions for supporting children of parents with multiple sclerosis.

*Keywords:* multiple sclerosis, children, parental MS, behavior issues, emotional, SES

### Emotional and Behavioral Encounters of Children with Parental Multiple Sclerosis

Multiple Sclerosis (MS) is a demyelinating disease that affects the central nervous system (De Judicibus & McCabe, 2004). MS affects about 2.5 million people worldwide and at least 200 new diagnosed cases per week in the United States (Tullman, 2013). MS is three times more prevalent in women than in men and is primarily prevalent among adults from 20 to 40 years of age (De Judicibus & McCabe). MS is one of the most common neurological diseases affecting young adults who are parenting young children (Northrop & Frankel, 2011).

Parents affected by Multiple Sclerosis often experience disruptions during their parenting years because of different symptoms resulting from their chronic illness (De Judicibus & McCabe, 2004). Several researchers have identified symptoms that are common among persons with MS. Symptoms include: fatigue, cognitive impairment, paresthesia, sexual dysfunction, loss of vision, loss of balance, tremor, digestive difficulties, unsteady gait, conceptual reasoning, speed of cognitive processing, as well as bladder or bowel dysfunction (Mohr & Dick 1998; Northrop et al., 2011; Schiffer, 1991). Researchers have suggested that persons with MS may experience periods of chronic disease exacerbation that is often followed by periods of either relapsing-remissions or a steady progression of the disease (Mohr & Dick, 1998). According to the National Multiple Sclerosis Society (2016), MS symptoms can vary widely among persons who are affected with this disease because of its effect on the central nervous system. As a result, MS is an unpredictable chronic illness that causes both physical and psychological disabilities within the person who is affected and it is likely to have implications on the health and well-being of their children, family members, and caregivers.

Children who have a parent with MS have demonstrated greater levels of psychosocial and behavioral difficulties when compared with children of parents without MS (Razaz, et al., 2014). Some psychosocial and behavioral difficulties observed in children who have a parent with MS are: anxiety, depression, hostility, constraints in interpersonal relations (Arnaud, 1992); internalizing and externalizing problems (Diareme et al., 2006); difficulties in relation to others (De Judicibus & McCabe, 2004). The psychosocial and behavioral difficulties experienced by these children place them at-risk for mental health problems when compared to the general population (Brandt & Weinert, 1998). The incidence and patterns of psychosocial adjustment and behavioral difficulties in this population of children have been well documented (Diareme et al., 2006; De Judicibus & McCabe, 2004; Turpin, Leech & Hackenberg, 2008), but less is known about how behavioral difficulties may influence their development as it relates to academic and career transitions. Therefore, this paper will provide information regarding the literature on psychosocial and behavioral difficulties in children who have a parent with MS and explore counseling strategies and effective interventions for supporting their holistic needs. Information from this review would be helpful for counseling professionals, educators, and researchers.

### **Emotional and Psychological Health of Children**

Researchers have conducted studies that provide evidence that having a parent with a physical health problem can place children at an increased risk of developing emotional and behavioral difficulties (Kelley, Sikka & Venkatesan, 1997; Korneluk & Lee, 1998; Romer, Barkmann, Schulte-Markwort, Thomalla & Riedesser, 2002; Wright, Reiser, & Delparte, 2017). Researchers have also explained how parental MS can cause a considerable amount of stress and anxiety on both their children and families. As a result, children of parents with MS are at greater

risk of having emotional, physical and social problems that can affect their quality of life and reduce their life satisfaction (Pakenham & Cox, 2012).

The emotional symptoms that have been identified among children of parents with MS include anxiety, depression, irritability, isolation, and anger (Arnaud, 1992; De Judicibus & McCabe, 2004; Diareme et al., 2006). These emotional symptoms can have serious implications on the mental health of these children, particularly because they are prone to lead to internal and external behavior disturbances and insufficient coping (Brandt & Weinert, 1998). (*See figure 1 for schematic depiction*). Among the emotional symptoms identified, anxiety and depression were the two most common symptoms in children who had a parent with MS. Cross et al. (1999) posited that one of the most common symptoms of anxiety identified in children of parental MS was distress. The authors further explained that children of parents with MS experienced distress for the following reasons; (a) they do not know anything about the disease, as a result, they were anxious about the disease process and how it may affect their family, (b) not knowing if MS was contagious and if they would acquire the disease, (c) having a lack of knowledge of how to care for an ill parent, and had become overwhelmed by the demand and responsibility (Schrag, Morley, Quinn & Jahanshahi, 2004), and (d) distress that led to fear because they did not want their parents to die. Children will demonstrate anxiety and if care is not given, it can lead to depressive symptoms (Mohr & Dick, 1998).

According to Mohr and Dick (1998) some depressive symptoms experienced by children who have a parent with MS were worry, anger, and discouragement. In Yahav et al.'s (2007) study ( $N = 216$ ), children with a parent MS showed a higher level of both anxiety and depression when compared with children whose parents did not have MS. The authors posited that the

difference in their results could be attributed to stressors such as discouragement and worry that causes additional difficulties for children who have a parent with MS. The authors also explained that these stressors can have implications for the psychosocial well-being of children in this group. This was supported by several studies conducted by researchers who have found that there are higher incidences of psychopathology among children with chronically ill parents (Compas, Connor-Smith, Saltzman, Thomsen & Wadsworth, 2001; De Judicibus & McCabe, 2004; Steck, Amsler, Dillier, Grether, Kappos, & Burgin, 2005). Unfortunately, many children who have a parent with MS experience their parent's disease process negatively. The emotional systems that develop from these negative processes lead to behavior difficulties.

### **Behavioral Functioning of Children**

Compared to the general population, children who have a parent with MS are more susceptible to behavioral difficulties. As a result, children who have a parent with MS are considered "at-risk" for mental health problems (Razaz, Tremlett, Boyce, Guhn, Marrie, & Joseph, 2016), psychosocial maladjustments (Barkmann, Romer, Watson & Schulte-Markwort, 2007), emotional problems (Razaz et al., 2014), and peer difficulties (De Judicibus & McCabe, 2004). The elevated risk of emotional and behavioral difficulties among children of parents with MS have negative implications for the health status and future quality of life for this group of children.

Worsham, Compas & Ey (1997) pointed out that a parents' chronic illnesses are a source of significant stress for their children. Gregory, Disler, and Firth (1994) study found that parents with MS also believed their illness influenced their child's adjustment and psychological state.

Arnaud (1992) pointed out that the psychological adjustment of children could be influenced by a parents' personality changes and the differences in the nature of the parents' MS symptoms.

Hops, Sherman, & Biglan (1990) reported that mothers who are depressed are more likely to use aversive processes in their interactions with family members, but are more likely to use coercive processes to manage their children's behavior. Deatrick, Brennan, and Cameron (1998) found that parent-child interaction is less positive during periods when parents are experiencing MS-related symptoms. This is a critical juncture because family dysfunction was a predictor for children externalizing problems as well as having illness severity for internalizing problems (Diareme et al., 2006). Whereas, parental conflict and increased tension between cohabitating couples with MS had a negative effect on children and placed them at-risk for a variety of developmental and emotional problems that lead to behavioral problems (Davies & Cummings, 1994; De Judicibus & McCabe, 2004; Reid & Crisafulli, 1990).

It has been well documented that parents MS has had an impact on children's emotional development. This is a concern because a child's emotional and behavioral health is important for their mental and physical well-being. Numerous studies have concluded that the problem behavior found in children is determined by the perception of stressfulness and a number of daily hassles of having a parent with a chronic illness, thus having a greater impact than the severity of the parent's illness (Dufour, Meijer, Port & Visser-Meily, 2006; Korneluk & Lee 1998). Children often react to stressors related to a parent's illness by isolating themselves, adopting feelings of guilt, and worrying about the perceived changes in their parent's health. There is evidence that paternal depression is a risk factor for the adjustment of children and adolescents (Field, Diego & Sanders, 2001; Shen, Manusson, Rai, Lundberg, Le-Scherban, Delman, Lee, 2016; Weissman,

Prusoff, Gammon, Merikangas, Leckman, & Kidd, 1984). This was confirmed by Pakenham and Cox (2012), who found that some children of parents with MS perceived that their feeling of anxiety and depression was as a result of trying to help their parents manage their sorrow and grief. Pakenham et al. (2012) also noted that some children pointed out that they think they were better adjusted and happier when they believed their parent was actively coping with their MS symptoms. According to Nelson and While (2002), there are several factors that may interact to have an effect on children's problem behavior. Some of these factors are; the child's age or gender; parent socioeconomic status (SES); and parent level of functioning. Children with parents who have MS often experience behavioral difficulties that can influence their school life.

### **School life of Children with Parental MS**

A parent's MS can affect their child's school life. Flickinger et al. (1994) explained that as a result of children fulfilling caregiving responsibilities to their parents, children had a difficult time staying focused and concentrating on their daily activities. Friedmann et al., 1987 found that children's antisocial behavior and reduced school performance was because of their caregiving responsibilities to a parent that was ill. The caregiving role and responsibilities that children presume can interfere with their schoolwork, providing less time to devote to completing homework. Equivalently, children who were involved in fulfilling caretaker tasks were at-risk for having regular school absences because of the personal obligation of taking care of an ill parent. Children who are absent miss out on age-appropriate activities at school and opportunities for socializing with their peers (Friedmann et al., 1987). This notion was supported by Flickinger et al. who reported that the children of parents with MS had less time to participate in extracurricular activities because of an urgent need to get home to their ill parents.



Overwhelmingly, researchers have found MS has negatively impacted their child's emotional state, behavioral functioning, and school experience (Arnaud 1992; Bogosian, Moss-Morris, Bishop & Hadwin, 2011; Cross & Rintell, 1999; De Judicibus & McCabe, 2004; Yahav, Vosburgh, & Miller, 2007). However, there are some studies that discuss children's ability to demonstrate resilience in one area of developmental (academic achievement), while they may continue to struggle in other areas (Moberg, Magyari, Koch-Henriksen, Thygesen, Laursen, & Soelberg Sorensen, 2016). This notion was supported by Moberg et al., (2016) nationwide qualitative study with knowledgeable persons ( $N = 37,593$ ), consisting of children ( $n = 4177$ ) of parents with MS and associated persons ( $n = 33,416$ ).

### **Caregiving Role of Children for a Parent with Multiple Sclerosis**

It is evident that parental MS can have a detrimental effect on children. Parents with chronic illness, have often become emotionally and physically inaccessible to their children for reasons, such as fatigue and exacerbation (Faulkner & Davey, 2002). The parenting modifications that may occur due to a parent's MS did not change the love, concern, and care that they had for their children, however there are inevitable modifications that exist with how they carry out their parenting. These modifications are related to physical symptoms (vision, motor skills, energy) and episodes of MS that may prevent them from partaking in particular tasks (i.e., driving, attending school events) (Aldridge & Becker, 2003). The change in parenting and interactions with parents who have MS can also result in the child adopting additional responsibilities for themselves, family parental roles (emotional, supervision), and being a contributor to the caregiving team for their parent (Faulkner & Davey, 2002).

Children often take the responsibility of becoming a caregiver because of a chronically ill parent. According to Björgvinsdóttir (2005), children taking the responsibility as caregivers to an ill parent are often unrecognized and hidden from society because of their youthful age. Therefore, they are not considered experienced or even responsible for taking on such a task. Aldridge and Becker (2003) explained that there are serious consequences to children being caregivers for a chronically ill parent. The authors highlighted that both the experiences and responsibilities of being a caregiver can seriously affect the well-being of a child-caregiver and will have future consequences as they transition to adulthood. Consequently, De Judicibus & McCabe (2004) posited that children whose parents have MS have demonstrated a false maturity reaction, and this could be as a result of their caregiving responsibilities.

The effects of disabling fatigues as well as disease exacerbation, followed by periods of remission are some of the problems parents with MS periodically experience (Mohr & Dick, 1998), and this will have an impact on both the physical and socioemotional state of a child-caregiver. As children assume the responsibilities of a caregiver, the normality of their childhood is lost (Flickinger et al., 1994). Flickinger et al. also explained that often children have little or no knowledge as it relates multiple sclerosis, and as a result, this inadequate knowledge about some aspect of their parent's condition can cause a child to feel stress, isolated and neglected. Blackford (1992) reported that because of a parent's ill health, children have to fulfill many of the household chores that had been previously the responsibility of the ill parent. As a result of the increased responsibilities and chores, this allows the child less time for social activities with others. This was supported by Lackey and Gates (2001) who found that children spend more time daily with fulfilling caregiving activities because of their parents MS. Children fulfilling

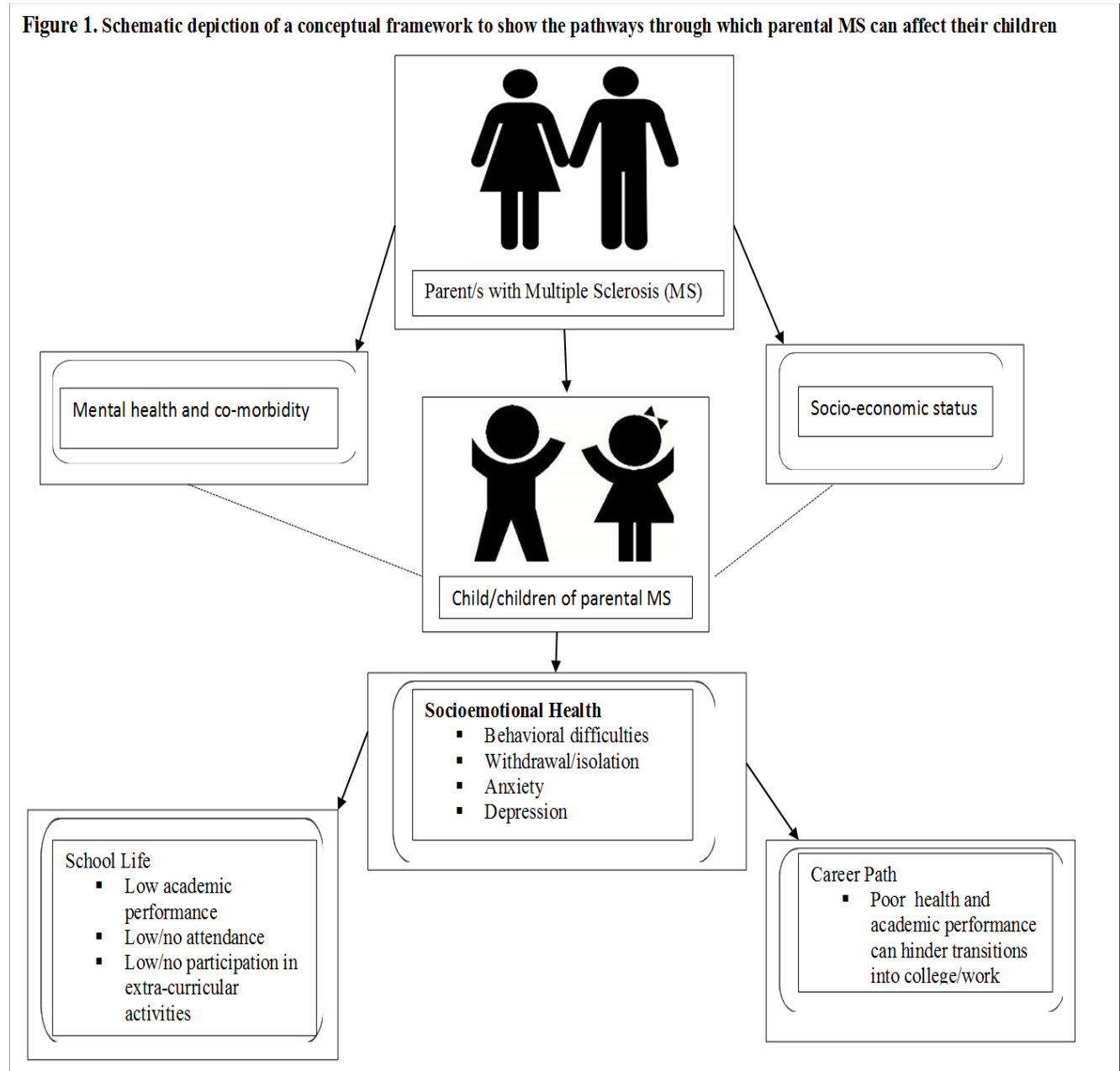
caregiving responsibilities to a parent with MS has affected them either, emotionally, behaviorally, socially or physically, and intervention is needed to help reduce and eliminate these effects.

### **The Impact of Parental Socioeconomic Status on Children**

According to Pakenham, Tilling and Cretchley (2012) stressors such as financial difficulties and a lack of formal supports can compound disabling symptoms produced by MS and make the quality of life more difficult. In fact, Forehand et al. (1998) found that children of low socio-economic status (SES) are shown to have fewer resources to deal with parental chronic illness than children of higher socio-economic status. The authors further explained that SES could account for increased difficulties in children adjustment. This was supported by De Judicibus & McCabe (2004) who posited that concomitant financial stresses can have an impact on children's behavior problems.

According to Brandt and Weinert (1998) study, children from higher socio-economic status households did not have a propensity for associated mental health problems because they lived in families who had adequate finances, resources to adapt, and more marital support. Booth and Johnson (1994) reported that financial problems have been shown to increase the effects of illness on a person's health and reduce their marital happiness. Additionally, a low socioeconomic status among an ill parent would have an impact on reduced resources and social involvement in order to cope with stressful events in life (Folkman et al., 1987). In fact, children of a single parent with an illness might have more difficulties adapting to their parent's illness because the children do not have another parent for support (Taanila, Syrjala, Kokkonen & Jarvelin, 2002). Researchers have shown that there is some evidence that financial hardship has a

negative impact on children and it is largely due to parental distress (Conger, Conger, Elder, Lorenz, Simons, & Whitbeck, 1993). Similarly, McMunn, Nazroo, Marmot, Boreham & Goodman (2001) reported that socioeconomic indicators are also associated with the emotional and behavioral difficulties in children, this is depicted in the pictorial format in *figure 1*. (See *figure 1 for schematic depiction*).



**Implications for Research and Practice**

Understanding the impact a parental multiple sclerosis has on the family unit especially their children should be of great concern for counseling professionals so that we can provide the best possible support and advocacy for these children. Having cultural competence, effective

interventions, and research-based strategies are of utmost importance to support the developmental progression and transitions of children, while it is also imperative that counselors avoid causing harm through potential misdiagnosis that may be cultural bound or can be explained as a situational occurrence during a limited time frame.

Emotional and behavioral difficulties have been linked to mental health problems of children who have a parent with MS (Razaz et al., 2016). Considering the heightened risk of mental health problems among children of parental MS, it is critical that counseling interventions are implemented quickly to reduce and eliminate the potential impact to these children. A vast amount of literature addresses the negative implications of psychosocial and social concerns that engender behavioral problems among children who have a parent with MS, which is considered a chronic illness (Korneluk et al., 1998; Razaz et al., 2016; Visser, Huizinga, van der Graaf, Hoekstra & Hoekstra-Weebers, 2004). Although children with parental MS have exhibited behavioral problems that often stem from their socioemotional and psychological adaptation that place them as “at risk children”, few studies have examined the impact these behavioral difficulties will have on both the children's academic performance and career path. In addition to the research that discussed the interference of psychological factors and various systems (school, family, community) that may interact with the development and successful progress of children with a parent with MS, there are also a few researchers that discuss the strengths of these children. Explicitly, as it pertains to their academic abilities and a desire to persist towards academic and career success, which are both notable indications of one's readiness and potential for future success. While prior literature discusses the risks and potential of children, there is limited research that discusses how the strengths of students and risks (i.e., psychological,

behavioral) can be mitigated through the efforts of counselor educators and counseling professionals.

### **Counseling Interventions to Support the Children of Parents with Multiple Sclerosis**

Counselors have an ethical responsibility to support and care for children whose parents have MS by cultivating their potential through collaborating with programs, parents, diverse experts, and school personnel (ASCA, 2005; ESSA, 2015; ISCA, 2011; ISCA, 2008; ACA, 2005; 2014; NCLB, 2004). It is imperative that counseling professionals identify any socioemotional and behavioral difficulties these children are experiencing and provide guidance, support and resources that are needed to help alleviate and modify the challenges they are experiencing. To address the children's academic performance, Adelman and Taylor (2008) suggested using the learning support or enabling component model. The primary goal of the learning support and enabling model is to evaluate and mitigate negative learning interferences by treating children with emotional and behavioral difficulties. This model would help to provide support to children while they transition to having an ill parent while still being academically able to function in school.

### **Support and Advocacy**

Support and advocacy have been a successful tool in enhancing socioemotional and behavior difficulties in people and would therefore be a great tool for children with parental MS (Barnard & McKeganey, 2004). Providing an educational and support group for both parental MS and their children would help children have better knowledge of the disease and help them interact with other parents and children who are experiencing the same or similar transition as having a parent with a chronic illness. Additionally, this would provide an opportunity for

children of parental MS to have a safe space to share their fears, anxiety and talk about fulfilling their role as caregivers. While listening and interacting with these children, counseling professionals would be able to get a better understanding of their thoughts and feelings, after which they would be able to identify effective strategies that would be beneficial to this group of children.

Along with support groups for children and parents, group therapy would provide even more benefits to children with a parent with MS. In group therapy, children may learn to grow emotionally by learning different coping strategies to help resolved unwanted behavior. A therapeutic factor that could be beneficial to children in group therapy is Yalom's eleven therapeutic factors (Yalom, 1985). Yalom's eleven therapeutic factors are very beneficial in influencing the process of change and healing among group members. More specifically, applying the Yalom's therapeutic factor can help group members recognize that they are not alone and that the problems they experienced are similar to others. As a result, Universality would provide children with a sense of belonging and inclusion (Yalom, 1985), because they would be around children who also have a parent with an illness and be able to relate based on common experiences. This can also assist with the development of their interpersonal relationships, as well as their emotional and physical wellness.

### **Recommendation**

It is evident that parental MS has had negative influences on their child's behavioral and socio-emotional state. It is also evident that their parents' condition impacts their child's academic performance. As a result, the authors recommend an interdisciplinary team of researchers conducts mixed methods concurrent triangulation design to gain a better



understanding of the daily experiences of children of MS, the hierarchy of variables that impact their emotional, behavioral, career progression, and academic performance. Supplemental action research and longitudinal studies may be beneficial to evaluate the progression, transition, and long-term effects that impact their decision-making process, coping, wellness, as well as, work to career transitions and trajectory. The qualitative sector could include focus groups with both parents with MS and their children, which would allow researchers to gain a better understanding of the interacting dynamics that impact their developmental progress and performance outcomes. From the information gathered, counselors would be able to get a better understanding of their experiences and would be able to use this information to develop research-based interventions and utilize strategies that are most suited and beneficial for this cultural group.

### **Conclusion**

There are limited studies addressing the behavior difficulties of children who have a parent with multiple sclerosis. As a result, it is difficult to draw conclusions regarding the behavior difficulties that exist among children from the existing research. From the limited research articles on parental MS and children's adjustment and functioning, it is important to note, parental multiple sclerosis has been associated with higher rates of depression, anxiety, isolation, as well as internalizing and externalizing challenges in children that have been associated with behavioral difficulties among these groups of children. Therefore, early interventions, such as counseling strategies, mentors, and psychoeducation groups that include coping skills are needed to help children whose parents have MS.

Counseling professionals working with children who have a parent with MS need to be aware of the effects of both behavioral difficulties as well as mental health co-morbidity

commonly found among groups of children with a parent with a chronic disease. A parent with MS needs support and the children of these parents are affected in many different ways because of their parent's illness. As a result, it is important to have available resources and support for this group of children in order to invest in their development and progression to become productive members of society who can impact future generations.

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