

Parental multiple sclerosis, changes in family routine and mental health of young children

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Abstract

Introduction: Parental illness generates changes in family dynamics and in the mental health of all family members. Children of parents with chronic illnesses, such as multiple sclerosis face unique challenges, as they are forced to adapt to a new reality where parental illness limits the care and attention capabilities towards them.

Methods: a systematic literature review was conducted using the PsycInfo, Scopus and Medline databases, with the equation "multiple sclerosis"; AND "family"; AND "parents"; AND "child parent relations", conducted in September 2022.

Results: n = 26 studies were included. Children of people with multiple sclerosis (MS) present more adjustment problems, anxiety disorders and behavioral disturbances than controls. This distress is associated with factors such as parental physical and psychological comorbidity and changes within family roles. The level of risk varies in relation to factors such as support network, sex of the ill parent, time of exposure to the disease and the role of the healthy parent. Lack of access to information and support turns out to be a common complaint of young children. Conclusions: Most of the children living with parental illness present experiences alterations in their mental health and show a higher prevalence of psychological distress; however, this does not occur in all cases. The most predominant protective factors seem to be: parental adherence to treatment, and, above all, access to effective information in accordance with the level of understanding of the different populations involved.

Keywords: Parental multiple sclerosis; Family; Mental health; Parental illness; Child welfare

1. Introduction

The diagnosis of a catastrophic disease, such as multiple sclerosis (MS), not only radically transforms the patient's life, but also reconfigures the family nucleus, altering its dynamics and structures in a profound way. Rolland (1) describes these alterations as non-normative crisis, which impose significant changes in all dimensions of human existence, including the family environment. These changes can range from the reassignment of roles to the modification of daily routines, affecting the quality of life of all family members, not only the patient.

Bužgová et al. (2) and Chen (3) emphasize in particular, how children of parents with serious illness face unique challenges, as they are forced to adapt to a new reality where the parents illness limits their abilities to care for and attend to them. This adaptation may be associated with their level of emotional and cognitive development, as it leads them to assume adult responsibilities prematurely (4). For example, Dharampal (5) and Dearden (6) mention how these young people are forced to take on caregiver roles, managing complex household tasks, assisting with mobility, administering medications, and even pursuing income-generating activities.

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This premature burden of responsibilities has a direct impact on their social and emotional life, limiting their opportunities for interaction outside the family environment and generating unbalanced social relationships (7). In addition, the constant concern for their parents' health can lead to concentration problems that can affect their school performance and generate difficulties to focus on their social life due to the concern for their sick or disabled family member (8).

Young children of people with chronic illness remain somewhat hidden from many social and health professionals, so limited scientific knowledge is available about the living conditions and experiences of this population (4). Because there is no comprehensive theoretical framework on parental chronic illness and its relationship to young children's mental health, more research efforts that integrate psychological, educational, socio-medical, and family process theories are needed, in order to improve understanding of the impact of parental illness on the psychosocial functioning of children and adolescents, and thus guide interventions that are tailored to their developmental level and guide responses to individual and family concerns (9).

1.1. Multiple sclerosis and its relation to parenthood

Multiple Sclerosis (MS) is a demyelinating disease that represents one of the most common neurological disorders, which is unpredictable and causes remitting and/or progressive physical and cognitive dysfunction; the disease affects young adults, mainly women (10). One in a thousand people are diagnosed with MS; it is estimated that there are 1.1 million people with MS worldwide (4).

MS presents with various symptoms such as: changes in sensation, muscle weakness and spasms, coordination and balance difficulties, speech or swallowing problems, visual problems, fatigue, pain, and bladder and bowel difficulties (11). It is usually accompanied by deficits in mental functions (language, memory, attention and executive function), which in turn are associated with psychological and psychiatric comorbidities (4).

MS presents itself in the form of acute episodes of undetermined duration that superimpose themselves on the underlying chronic disease and produce new anomalies and/or significant worsening of the existing ones; due to their unpredictability. These episodes are closely related to anxiety, anger and guilt (12). Reactions to this distress depend on factors such as the dramatic onset of the disease and the time elapsed from the first symptoms to diagnosis (13).

MS is a neurodegenerative disease that appears between 20 and 40 years of age, a stage of life in which parenting is an important issue (12). It is estimated that about 75% of MS patients are women of reproductive age (10), so, at the time of disease onset, children and adolescents are a dependent part of the family nucleus of the person who became ill (14).

Most female patients with MS decide not to become pregnant after diagnosis, mainly because of concern that their disease will interfere with their ability to raise children and because of concern about financial resources (10). Studies of patients with MS who have had children suggest that there is a clear relationship between acute episodes of the disease and a decrease in maternal affection for the children, which has led to less satisfaction with life for these children and therefore mental health-related problems (14).

MS also affects the parenting of the non-diagnosed parent, as most "healthy parents" neglect their own needs and repress their feelings in an attempt to manage and prioritize the needs of their family. Several partners of people with MS described trying to manage everything, practically and emotionally, to compensate for what their partners could not do because of the disease (13).

2. Methods

A literature review was performed following PRISMA guidelines. PsycInfo, Scopus, and Medline databases were used in the search. The search was conducted in September 2022, and the search equation was "multiple sclerosis"; AND "family" AND "parents" AND "child parent relations".

The inclusion criteria were: a) studies that provide information on the family dynamics of groups with parents diagnosed with MS who have children or adolescents; b) articles published in English and/or Spanish. Exclusion criteria were: a) populations other than those stipulated; b) families affected by pathologies other than MS; c) articles in languages other than English and Spanish.

The selection of the studies was carried out independently by the author in four stages: first, the title and abstract of the studies were read; second, the full text of the articles considered as potential was read. A critical reading of the papers

was performed to evaluate and identify biases in the methodology (Figure 1). The following variables were collected for each study: year of publication, country where the study was conducted, study design, sample size and main results. A descriptive analysis of the studies was performed.

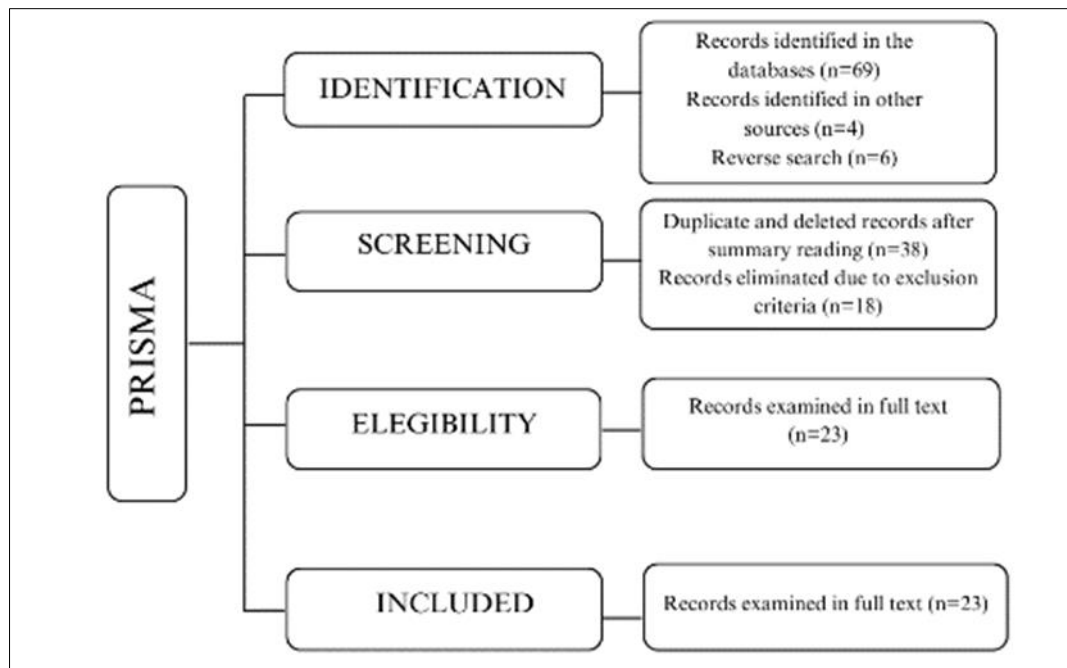


Figure 1 Summary of study selection

The search showed 69 papers in databases, another 4 papers were found in other sources. Thirty-eight articles were excluded after reading the title and abstract because they were duplicates or were not related to the subject of the study. After this phase, 35 full-text publications remained, of which 18 were excluded because they did not fully meet the inclusion criteria. Through a reverse search, 6 more articles were added. The sample consisted of n = 23 studies.

Most studies used the semi-structured interview as the research method, others used standardized psychometric tools. The selected studies were conducted in Canada, England, Australia, Israel, Sweden, Iceland, United States, Greece, Norway and Switzerland. No studies were found in Latin America. The following variables were collected for each study: reference, country where the study was conducted, sample size and main results, which are described in Table 1.

Table 1 Summary of studies

Reference and country	Type of study	Sample	Important findings
(4) Iceland	Qualitative	n= 11 CMS a=5-18	CMS feel invisible and unrecognized as caregivers for their parents. Caregiving activities can generate emotional distress, exhaustion, and the feeling of living a restricted childhood
(11) United Kingdom	Qualitative	n= 11 CMS a =13- 18 n=11 PMS a=40-60	Having a parent with MS is not directly related to adaptation difficulties; on the contrary, it can generate greater independence in the child. Single-parent families could have a worse adaptation. The negative impact of parental MS is related to the characteristics of the disease, care responsibilities, support network and changes in social relationships.
(13) Sweden	Qualitative	n= 9 CMS n= 9 PMS n= 5 C a= 12-24	Children and partners feel concerned about the parent with MS and show difficulty understanding and coping with symptoms such as: fatigue and emotional and cognitive alterations.

(15) USA	Quantitative	n=60 CMS a=7-16	CMS score high in: body concerns, dysphoria, hostility, limitations in interpersonal relationships, and dependency cravings. The results of daughters are less favorable than those of sons
(16) Canada	Quantitative	n=33 CMS a= 12-18 n= 33 C a=15	Families with parents with MS show higher rates of conflict and lower rates of cohesion, intellectual-cultural orientation, moral-religious emphasis, and organization.
(17) USA	Quantitative	n=174 CMS a=7-17	Compared to normative data (12-20%), 26% children of people with MS are at risk of mental health problems
(18) United Kingdom	Quantitative	T1 n=75 CMS a= 12-19 n=56 PMS a= 34-60 n=40 PC T2 n=62 CMS n=48 PMS n=33 PC	High depression scores in parents with MS were correlated with increased internalizing symptoms in their children, while high scores on the assessment of expressed emotion were associated with increased externalizing symptoms. No direct effect of MS severity, duration, or type was observed.
(20) Greece	Quantitative	n=56 CMS a= 5.1-14 n= 64 C a= 5-15.9 n= 101 PMS and couples a= 34.8-47.9 n= 128 PC a= 35.9-50	CMS, especially those whose mother is diagnosed, present more emotional and behavioral problems. Family dysfunction predicted children's global and externalizing problems, whereas severity of the ill mother's impairment predicted children's internalizing problems.
(21) Swiss	Qualitative	n=37 ♀ CMS a=11.2-7 n=35 ♂ CMS a=12.5-6.4	The emotional and cognitive factors of patients with MS do not predict the coping capacity of their children; however, the coping capacity of the healthy couple is related to that of the children.
(22) Norway	Qualitative	n=15 CMS a=12-18	The "balance of needs" explains the effects of parental MS and how children are negatively and positively affected in their roles and responsibilities. Children are characterized by: not talking to anyone outside the family about MS, experiencing little support from healthcare personnel and having little knowledge about the disease..
(23) Sweden	Qualitative	n=9 CMS n= 9 PMS n= 5 PC	Families with a parent with MS highlight the need to be well informed about the disease at the time of diagnosis and throughout the course of the disease, focusing on the maturity level of the recipient.
(24) Australia	Quantitative	T1 n= 85 PMS a=44.2±5.2 n=55 PC a= 55 ±5.52 n=130 CMS	CMS who are responsible for socio-emotional and instrumental care show worse psychological adjustment at follow-up. Demanding care responsibilities are associated with low life satisfaction, somatization problems, and, in general, greater difficulties. Those who take care of their emotional well-being show better psychological adjustment.

		a= 14.2 ± 3.1 T2 n=71 PMS n=48 PC n=91 CMS	
(25) Canadá	Quantitative	n=153 CMS a= 5.7 ±0.3 n=876 C a= 5.7 ±0.4	Comorbidities in mental health is more common in parents with MS, which is associated with greater vulnerability of HEMs in social competence and emotional maturity. The longer the time of exposure to the disease, the greater vulnerability they present in the physical health domain.
(26) Swiss	Qualitative	n= 87 CMS a= 3-26	The ability of CMS to cope with the disease is determined by the coping style of the healthy parent, especially that of the same sex. Daughters cope better than sons, regardless of the sex of the parent with MS. Only the daughter's coping is positively affected by the age and illness variables. Healthy mothers and daughters cope better with the father's increasing disability.
(27) United Kingdom	Quantitative and qualitative	n= 131 CMS	Educational activities that explain MS give families the confidence to talk about the impact of the disease on their lives and have the potential to change health-related behavior..
(28) Canadá	Qualitative	n= 8 CMS a= 7-14	Additional responsibilities can improve the skills of children of parents with MS and provide both pride and stress. Excessive responsibilities could limit participation in educational and recreational activities, generating anxiety and isolation. Activities like peer bonding can be beneficial.
(31) Australia	Quantitative	T 1 n=85 CMS a= 44.7 ±5.2 n= 127 CMS a= 14.2±3.1 T 2 n=70 PMS n= 90 CMS	The redistribution of roles, stress and stigma were involved in the processes that link the disability of parents with MS with the children's adaptation domains. Parental depression affects family functioning and mediates the effects on children's adjustment.
(32) Israel	Quantitative	n= 56 CMS a=14.6±2.2 n= 156 C a=14.1±1.7	CMS reported more intense emotions, greater levels of obligation, responsibility, and concern for their parents. Showing more anxious-depressive symptoms than controls.
(33) Canadá	Quantitative	n= 783 CMS a= 5.7 ±0.3 n=2988 C a= 5.7 ±0.4	Maternal MS is related to greater vulnerability in development, especially social development. Parental MS was not independently associated with developmental vulnerability in offspring, but CSM and physical presence is a risk factor.
(34) USA	Qualitative	n=21 CMS a= 9.93±1.94	CMS show a lack of knowledge about the symptoms of the disease, which makes their perception of the sick parent and the relationship with them complex.
(37) Australia	Quantitative	n=20 CMS a= 9-14 n= 14 PMS a= 39 ±5.02	Interventions with CMS are related to a significant decrease in: anguish, stress, caregiving compulsion, and activity restrictions. They also increase social support and knowledge of MS.

(38) Greece	Quantitative	n=56 CMS;56 PMS; 56 PC a=4-17	CMS who have partial information about their parents' illness score higher on the scales: social problems, internalizing problems and total problems. Those who have complete information or those who have no information show more adaptive behavior
(39) Canadá	Qualitative	n=22 CMS	Parental MS has more positive factors than negative ones. In the positive ones, the perception of good quality of life stands out, in the negative ones, little knowledge about MS and feelings of fear, anger and sadness stand out.

CMS children of people with MS; C control; PMS parents with multiple sclerosis; PC parents of the control group, a age; n sample

3. Discussion

The interest in the study of psychological aspects of young children living with MS dates back to the late 1950s, the pioneer researcher in conducting a study that considers these two variables was Sara Arnaud who determined that this population is characterized by symptoms related to body concerns, dysphoria, hostility, limitations in interpersonal relationships and longing for dependence (15).

Subsequent studies focused on determining the family functioning of people with MS, finding that these families are characterized by living together with greater conflict and less cohesion (16). Thereafter, more contemporary studies have determined that, although the psychological profile of the children of people with MS varies according to the unique factors that characterize each family and individual, there are more mental health problems in children who have a parent with MS versus those who live with a healthy parent (11, 17-28) and that it is not the disease itself that generates discomfort, but the attitude that the family take towards it.

The analysis of the scientific literature made it possible to identify four variables that play a leading role in the analysis of the dynamics of families with children living with MS and their relationship with mental health, whilst also trying to highlight the complexity of the repercussions of MS on family structure and functioning, emphasizing the importance of considering both the direct and indirect effects of the disease in association with socio-environmental variables.

3.1. Changes in the family routine and redistribution of roles

The disease causes discomfort and decreases the quality of life of the family group mainly due to the need for readjustment of routine of all its members (2, 29). It is known that children of people with MS assume more responsibilities than their peers, and given the typical deterioration of the disease, the responsibilities they assume include: domestic care, emotional support, personal care and care of siblings (30). This, according to Bogosian et al. (11), leads to both positive experiences, such as greater empathy and maturity, and negative ones, including family tensions and worries about the future.

Pakenham (31) examined how, in the context of changes in routine and role redistribution, the variable disability of parents with MS plays an essential role. They found that along with parental disability came an increase in self-perceived stigma, which was the cause of a significant reorganization of roles within the household. This study showed that parental disability increased stress in children and adolescents with a standardized indirect effect of -0.20 ($p = .01$).

Changes in the family routine, when unbalanced, are one of the main risk factors for the development of mental health problems in its members. Demanding caregiving activities and responsibilities have been associated with psychological distress such as: low life satisfaction and somatization problems (31), problems in maintaining healthy interpersonal ties (11), tendency to isolation and increased depressive anxiety symptoms (28,32).

3.2. Mental health morbidity

Razaz et al, (33), through population-based retrospective cohort study focused on early child development, concluded that, despite the developmental profiles of children with a parent with MS (n=153) were similar to children of unaffected parents (n=876) in all domains assessed, there is a high mental health morbidity that was more common among parents with MS compared to parents without MS (49.5% vs. 35.3%). Psychological morbidity was associated with children's vulnerability in the domains of social competence (OR, 5.73 $p < .05$) and emotional maturity (OR, 3.03 $p < .05$).

At later ages, there is a significant relationship between the father's depressive symptomatology and manifestations of internalizing and externalizing problems in the children (18,20). Based on a longitudinal study, which included baseline and 6-month follow-up data of 75 adolescents, their 56 parents with MS and 40 partners without MS, reveals that higher

depression scores of parents with MS correlate with increased internalizing symptoms in adolescents at 6-month follow-up ($r=0.31$, $P=.004$). Higher scores of elevated emotional expression by parents with MS were associated with an increase in adolescents' externalizing symptoms at the 6-month follow-up ($r=0.35$, $P=.052$). Of note, no direct effect of severity, duration, or type of MS on adolescent adjustment was found (18).

Corroborating this trend, Diarem et al. (20) noted that children with MS-affected mothers reported significantly higher scores on both internalizing ($M = 10.70$) and externalizing ($M= 12.62$) problems, compared with children whose mothers did not have somatic diseases ($M= 6.13$, and 7.29 , respectively), with statistically significant differences ($p < .001$).

Likewise, Pakenham (31) showed that parental depression showed a direct and significant relationship with family conflict ($p < .01$), cohesion ($p < .01$), and somatization in youth. The interaction between parental disability and parental depression stood out as a significant predictor of behavioral and social difficulties in youth ($b = -0.63$, $p = .02$), suggesting that increasing these parental conditions exacerbated problems in children. Parental mental health morbidity is a complex issue not only because of the effect it has on the dynamics of the family group, but also because it was found that depressive-type distress was negatively correlated with the coping capacity of patients with MS ($r = -0.41$; $P < 0.05$), which strengthens the risk factors as it limits the resources that allow coping with this difficulty (21).

3.3. Sex and gender

There appears to be a close relationship between the sex of the parent with MS and the coping skills of the children. Diarem et al. (20) observed that children of mothers, but not of fathers, with MS presented greater problems than children in the control group; however, they acknowledge that this finding could be related to the small sample of sick fathers in the study. They further mention that this could be attributed to the possible lower degree of exposure of the children to paternal illness, compared to maternal illness, due to the more limited involvement of fathers than mothers in child care, especially when fathers are ill, highlighting the role of gender roles in these dynamics.

Razaz, Tremlett, et al., (25) found that children of mothers with MS showed higher rates of mood or anxiety disorders (HR 1.7, $p < .05$) compared with those whose fathers were unaffected, implying that the mental health morbidity of the ill parent plays a mediating role in this increased risk. However, no increased rates of these disorders were observed in children of parents with MS (HR 0.5, $p < .05$), suggesting a specific transmission pattern related to maternal MS.

On the other hand, Steck et al. (26) focused on the influence of gender on coping ability within families with MS, finding significant differences based on the gender of the sons. Daughters showed higher coping ability (IQs of 3.23 and 3.25) compared to sons (IQs of 2.82 and 2.97), regardless of the gender of the parent with MS. A significant correlation in coping patterns was observed between parents and children of the same gender, indicating more effective disability management by healthy mothers and their daughters, a dynamic that did not extend to relationships between healthy fathers and their sons.

3.4. Limitations on access to information

Cross & Rintell (34) determined that, in the context of parental MS, one of the most representative risk factors is the children's limitations in understanding their parents' disease, and concluded that the inability to understand the symptoms associated with the disease was related to changes in their perception of the father and, therefore, in their relationship with him. This highlights the need to strengthen access to communication as a protective strategy.

The key to effective communication with children and adolescents lies in developing and maintaining relationships with them, providing information appropriate to their developmental level, and creating opportunities for them to express their feelings and preferences (35). The ability to establish safe communication in the context of parental illness prevents the holding of misconceptions associated with parental illness, which are related to poorer psychological adjustment (36). Communication facilitates the understanding and acceptance of the impact of the disease on the dynamics and roles within the family, which is associated with a reduction of stigma and stress, with the promotion of healthy coping strategies through learning that they can ask for and receive help not only from those close to them but also from health personnel, and even from the school (9,37).

One of the central points of most of the studies reviewed is that there is a lack of adequate communication around MS, resulting in a poor understanding of children and adolescents about their parents' disease (19). This, according to Paliokosta et al. (38), is related not only to a decline in the relationship with the parent, but also with the relationship they have with themselves, mainly because catastrophic ideas about MS are related to poorer psychological adjustment.

Although the field of study of the impact of parental illness on young children has not been widely studied, the study by Diareme et al. (20) presents useful clinical guidelines, including the promotion of illness-related knowledge and coping skills in children and the selection of treatment goals and intervention techniques according to the developmental needs of the child, the family, and the stage of parental illness.

Specifically for children and adolescents from 5 years of age onwards, he highlights the benefit of using written and illustrated materials to familiarize them with concepts or procedures, in addition to highlighting the benefit of literary techniques. She also emphasizes how it becomes essential for adolescents to maintain considerations related to issues of identity and independence, and the need to ask about their preferences (20). The lack of understanding of the disease is associated with a tendency of isolation, as there is no confidence to talk about this situation with people outside the family nucleus, restricting the support network in a significant way (22). This makes it necessary to demand effective information (39) be adapted to the developmental level of the recipients, as well as to propose educational and interactive activities that generate positive impacts (27).

3.5. The other side of the coin: are they all adverse effects?

In addition to the adverse effects in terms of mental health, some studies found beneficial effects for children and adolescents. Among them, reference is made to increased empathy and responsibility, strengthened family bonds or pride in children's administrative and caring skills (11,24,28,39).

There is also evidence that children of parents with MS may come to feel happy and adjusted when they see their parents actively coping with the disease, taking their medication, resting, seeking alternative treatments and being socially active (12). Some of the children and adolescents of people with MS described feeling satisfaction and pride in their increased caregiving tasks (22), as well as developing a greater level of independence (18).

4. Conclusion

MS, due to its unpredictability, generates uncertainty in the daily life of both the person who receives the diagnosis and those who live with it. In the context of parental illness, the lack of availability caused by factors such as the need for health care or the discomfort generated by the disease, makes children assume care tasks that are not always in accordance with their level of maturity, thus generating conflicts associated with the redistribution of roles within the household, stigma and stress.

Most of the children living with parental illness present alterations in their mental health and show a higher prevalence of psychological distress; however, this does not occur in all cases. The most predominant protective factors seem to be: parental adherence to treatment, and, above all, access to effective information in accordance with the level of understanding of the different populations involved.

Compliance with ethical standards

Disclosure of conflict of interest

No conflict of interest to be disclosed.

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