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Psychosocial adjustment in children and adolescents with a parent with multiple sclerosis: a systematic review

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Objective: This systematic review explored the potential impact of parental multiple sclerosis on their offspring. It considered adjustment to parental multiple sclerosis at different developmental stages and the factors associated with good versus poor adjustment.
Data sources: MEDLINE, EMBASE, PsycINFO, CINAHL and Web of Science were searched for studies on children with a parent with multiple sclerosis. Inclusion and exclusion criteria were formulated. Hand-searching journals and reference lists, contacting authors and multiple sclerosis societies for additional unpublished papers complemented the searches.
Review methods: Twenty studies that satisfied the inclusion criteria were included. The research articles were ranked according to a quality assessment checklist and were categorized as good, medium or poor quality.
Results: The review found good evidence to suggest that parental multiple sclerosis has a negative impact on children's social and family relationships and their psychological well-being. The review also identified potential factors associated with poor adjustment. These factors included parental negative emotions, increased illness severity, family dysfunction, children's lack of knowledge about the illness and lack of social support. Adolescent children also seemed to be more at risk for psychosocial problems than school-age children.
Conclusions: There is good evidence that parental multiple sclerosis has a negative psychosocial impact on children, especially on adolescents.

Introduction

There is increasing evidence that having a parent with a physical health problem can place children at an increased risk of developing emotional and behavioural difficulties.[1–3] Children of parents who experienced chronic headaches demonstrated a higher degree of somatic complaints, and poorer adjustment and social skills compared with children of 'healthy' parents.[4] Similarly, children of parents with cancer have been shown to experience elevated depression and anxiety.[5–7] Furthermore, studies on children of a parent with brain injury have shown that younger children compete with the injured parent for the well parent's attention and that older children may respond to family stress with acting-out behaviour such as school truancy and running away.[8] These children have more stress and insecurities in peer relationships,[9] and have poor relationship with the injured parent.[10]

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However, the impact on children of having a parent with a physical illness is not always negative. A literature review of the potential effects of having a parent with chronic renal failure concluded that there are both negative (e.g. depression, underachievement) and positive (e.g. enhanced self-esteem) effects on children.[11]

Research has also explored the impact on children of having a parent with multiple sclerosis. Multiple sclerosis is more common in women than men, with a ratio of 1.5 : 1.[12] It is an unpredictable, demyelinating disease of the central nervous system and causes either remitting or progressive physical and cognitive dysfunction. Multiple sclerosis presents with a variety of symptoms, including changes in sensation, muscle weakness and spasms, difficulties with coordination and balance, problems in speech or swallowing, visual problems, fatigue, pain, and bladder and bowel difficulties.[13–15] In addition, patients with multiple sclerosis are at risk of developing depression[16–18] and anxiety.[19,20] Compared with other conditions (such as physical disability, visual and hearing impairment) individuals with multiple sclerosis are also more likely to experience job loss.[21] All these factors make multiple sclerosis a particularly challenging illness for families.

The purpose of this review was to provide a systematic and critical overview of the existing literature on the associations between parental multiple sclerosis and adjustment in their offspring. It focused on two main themes based on existing literature. The first theme, addressed in Part 1, considers the negative and positive impact of parental multiple sclerosis on school-age children (age 5–11) and adolescents (age 11–18). The aim of the second theme addressed in Part 2 was to identify potential moderating psychosocial or parental illness factors on child outcome.

Method

Search strategy

Database searches were carried out in PsychInfo, MEDLINE, EMBASE, Web of Science (WoS) and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) to identify relevant studies on children with a parent with multiple sclerosis. The time period of the search ranged from the date each database begins to August 2008 (i.e. PsychInfo begins at 1806, MEDLINE at 1950, EMBASE at 1974, WoS at 1981 and CINAHL at 1982). For each database, the terms ‘parents’ and ‘multiple sclerosis’ were combined in each search (see details in Appendix 1 (online only)). ‘Children’ and ‘child’ were originally included in the search terms, but were removed due to the number of irrelevant articles they identified (especially articles on children with multiple sclerosis or articles on hereditary risks for children with a parent with multiple sclerosis).

In addition to this, the reference lists for all studies for which hard copies were obtained were examined. Two of the journals with the highest frequency of articles that fulfilled the inclusion criteria, *Multiple Sclerosis* (since 1998), *Research Nursing* (since 1953), and an online journal, *International Journal of MS Care* (since 1999), were then hand-searched to check for articles that might not have been included in the databases. The title and abstract of each article, and the full article where necessary, were screened against the inclusion criteria (Table 1) by the first author.

Following this process, four authors of the most recently published included studies were contacted to ask whether they were aware of any unpublished studies. Six charities which fund research on multiple sclerosis (MS Society Canada, MS Trust (UK), MS Society New Zealand, MS Society Australia, National MS Society (USA) and MS Society UK) were also contacted.

Study quality

Before review, the research articles were ranked according to a quality assessment checklist adapted specifically for this particular review (Appendix 2 (online only)). The quality assessment checklist for the quantitative studies extracted those criteria that were considered relevant to the studies included in this review from existing quality assessment lists.[22,23] In addition, based on consultation, criteria F, I, J and K were developed to cover all sections of the articles. Similarly, the quality assessment checklist for the qualitative studies was based on the checklist of Elliott *et al.*,[24] adding criterion F which was considered relevant. For each item in the quality list the first author rated each study as either positive or negative to provide a total quality score which was calculated by counting the number of validity/precision items rated positively. Any areas of uncertainty were cross-checked with the second author.

Based on this total score, a study was categorized as good, medium or poor quality. Quantitative studies that had satisfied 10–12 (83% or more) of the criteria were classified as good, those that satisfied 7–9 (58% or more) were classified as medium and those that satisfied less than 6 (50% or less) as poor quality. Similarly, qualitative studies that had satisfied 8–10 (80% or more) of the criteria were classified as good, those that satisfied 5–7 (50% or more) were classified as medium and those that satisfied less than 5 (less than 50%) as poor quality.

Results

Figure 1 shows the process of the inclusion of studies in this systematic review. Overall, 19

Table 1 Inclusion and exclusion review criteria

Criteria	Inclusion	Exclusion
1	Either a child's or parent's perspective of impact of MS on children	Studies that included children with a parent with MS as a subgroup of the sample, where the results were not presented separately from the other participants
2	Empirical studies of children and adolescents with a parent with MS	Articles that were not empirical studies of psychological factors involved in children with a parent with MS. (e.g. clinical reports, reviews, comments, experiences, case studies, or opinions)
3		Dissertation abstracts
4		Articles that did not have any statistical or qualitative analysis of the stated psychological factors
5		Articles published in languages other than English

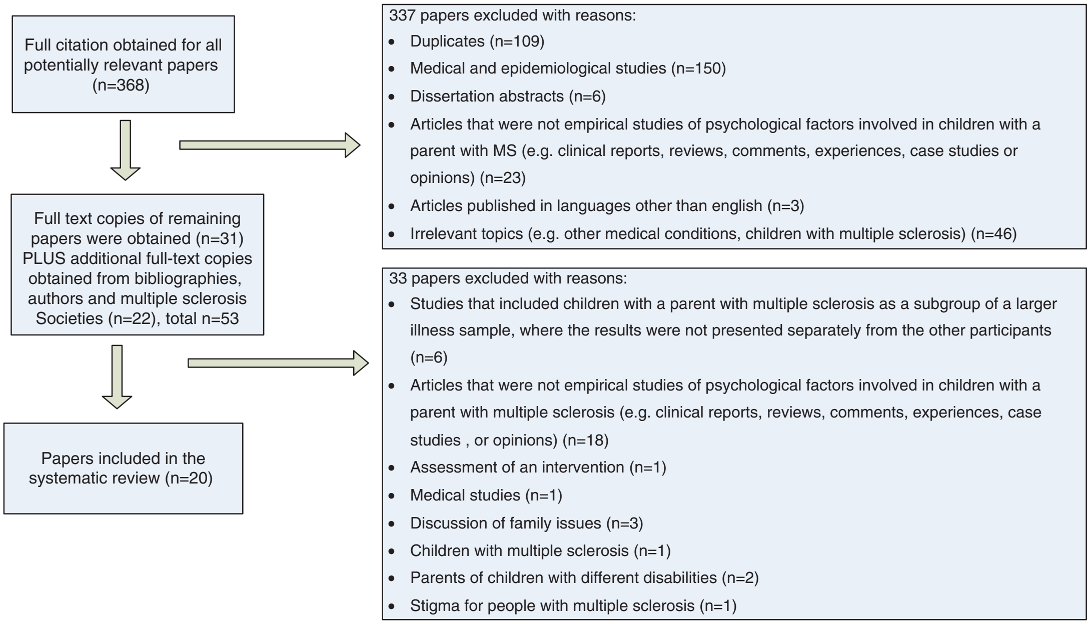

Figure 1 Process of inclusion.

published plus 1 unpublished studies met the inclusion criteria. The summary of all studies included are presented in Table 2. In order to make the heterogeneous data more comparable, the studies were grouped by research questions. The first section addresses the first theme and reviews the articles that investigate the possible impact of parental multiple sclerosis on children at different ages. The second addresses the second theme and looks at the research on psychosocial moderating factors. Papers of good and medium quality will be discussed here.

Part 1: The possible impact of parental multiple sclerosis on children at different ages

School-age children (7–11 years old)

Four[25,26,28,29] of the five studies[25–29] that were conducted either exclusively on school-age children[25,26] or analysed the results of school-age children separately[28,29] showed no significant impact of multiple sclerosis. One good and one medium quality case–control study found no differences between children with a parent with multiple sclerosis compared with children with a 'healthy' parent in mother–daughter interaction during work and play tasks[25] and self-image distortion.[26] Children (6–12 years) with a parent with multiple sclerosis in remission in a medium quality qualitative study reported an overall good quality of life. However, they also highlighted feelings of sadness and fear.[29] Only one good quality study using the Rorschach test (a test designed to understand personality and emotional adjustment[30]) found an adverse psychosocial impact on school-age children with a parent with advanced stage multiple sclerosis.[27]

Adolescents (11–18 years old)

All the studies conducted on adolescents indicated some negative impact on their psychological well-being.[27–29,31–33] Two good studies[27,32] and one medium-quality study[33] found that adolescents with a parent with multiple sclerosis experienced more fear and anxiety relating to their parents' stage of illness,[32] greater degree of separation anxiety, higher levels of depression[33] and increased body concern and hostility[27] when compared with adolescents with 'healthy' parents. Moreover, in a medium quality interview study, adolescents reported having a good overall quality of life; although they reported worry about 'getting' multiple sclerosis, as well as increased fear and anger.[29] Research findings also highlight that adolescents with a parent with multiple sclerosis had more responsibilities and experienced a negative impact on their social and family life compared with adolescents with 'healthy' parents.[27,29,31,32]

Studies that have not differentiated between age groups

Eight more studies have looked at the impact of parental multiple sclerosis and included children aged 4–25 years old but they did not differentiate age groups in their analysis and presentation of the data.[34–41] One of these studies[34] did report a comparison between younger and older children's scores on the child behaviour checklist and found no difference, but the comparison was between children aged 4–11 years old (parental reports) and children aged 12–17 years old (self-reports). The accuracy of comparing self and parent report is unclear.[42]

Seven of these eight studies found that children with a parent with multiple sclerosis have an increased risk of developing psychosocial problems.[34–39,41] Three studies, one good and two poor quality showed that children with a parent with multiple sclerosis had an increased risk for mental health problems compared with children with 'healthy' parents[34] or with general population norms.[38,39] In addition, according to the results of a good quality case–control study, they were also found to experience greater family responsibilities and lower life satisfaction.[37] Furthermore a good-quality qualitative study reported that children expressed anxiety about their parent's health and well-being.[41] Of these eight studies, only one poor quality qualitative study reported a positive impact on children.[40]

There are some limitations of the studies reviewed. First, some case–control studies used different recruitment processes and different

Table 2 Studies on children and adolescents with a parent with multiple sclerosis

Ref.	Aim	Design	Sample	Outcome measures	Key results	Quality scores
41	Explore experiences of children with a parent with MS	Qualitative	8 children (7–14 years old). Parental functional status varied	Interview on children's day-to-day lives, their perceptions of their parent's condition and their thoughts about the future	Children described taking on additional roles and responsibilities that restricted their participation in developmentally appropriate occupations	Good (9/10)
44	To estimate family's quality of coping with MS	Cross-sectional	44 patients, 36 healthy partners and 72 children	EDSS, BDI, CI	None of the patient variables predicted the CI of the healthy partner and the children	Medium (9/12)
36	Evaluate the prevalence of psychological symptoms in the offspring of people with MS	Cross-sectional	144 patients, 109 partners, 192 children	ACBC (parents), YSR (children over 11 yrs), BDI (parents), FAD (parents and children over 11 yrs), KI (doctor)	Ill and depressed parents evaluate their children as having more severe mental health problems	Good (10/12)
33	Separation-individuation processes of adolescent of parents of MS	Case–control study	56 children (10–18 yrs) 156 children control group	YSR, Separation Individuation Test of Adolescents	Children with a parent with MS showed higher depression and anxiety and higher separation anxiety	Good (10/12)
37	Examine adjustment in children with a parent with MS	Case–control	48 children (10–25 yrs) with a parent with MS versus 145 children without MS parent	Brief Social Support Questionnaire Brief Symptom Inventory, Satisfaction with Life Scale (children's report only)	Children with a parent with MS had poorer adjustment, greater family caregiving responsibilities and lower levels of life satisfaction and positive affect	Good (10/12)
34	Factors associated with emotional and behavioural problems	Case–control	56 MS patients and their spouses and 1 child (4–17 yrs) 64 children with healthy parents	ACBC (parents), YSR-children over 11 yrs, BDI (parents), FAD (parents and children over 11 yrs), KI (doctor)	Children with a parent with MS had higher emotional and behavioural problems Family dysfunction was a predictor for externalizing problems and illness severity for internalizing problems	Good (11/12)
38	Evaluate the need for psychotherapy.	Qualitative and cross-sectional	41 children (6–18 yrs)	Semi-structured interviews, TAT, story stems drawing of parents, self dreams	Half of the children were estimated to benefit from individual psychotherapy. Risk for mental health problems in children. Depression in a parent and single parenthood present an unfavourable context	Poor (6/12)
32	Children's feelings towards parent with MS	Case–control study	56 children with parent with MS (10–18 yrs) 156 children control	Questionnaire developed for the study (children's report only)	Adolescents with a parent with MS felt more responsible and obligated, reported more yielding behaviour, more fear and anxiety related to stage of illness, greater sense of burden, greater degree of anger	Good (10/12)

(continued)

Table 2 Continued

Ref.	Aim	Design	Sample	Outcome measures	Key results	Quality scores
35	Examine risk of psychopathology for children with a parent with MS	Cross-sectional	31 MS parents (29–53 yrs; 2 benign, 28 relapsing–remitting) 48 children (4–16 yrs)	SDQ Profile of Mood States, Family Income, Kansas Marital Satisfaction Scale (parental reports)	Children with a parent with MS were at greater risk for peer problems than the general community. Parental negative affect predicted parental reports of peer problems on their children	Medium (9/12)
28	Evaluate the need for intervention for children with a parent with MS	Survey	82 children (12–18 yrs) 95 adult offspring 191 parents	Questionnaires designed for this survey (both parents' and children's reports)	MS had an impact on the children's emotional development, participation in recreational activities, activities with friends and did not have an impact on school performance and physical activities	Poor (4/12)
45	Evaluate how parents' coping affects their children's capacity to cope	Qualitative and cross-sectional	52 families (patients with severe disability) and 87 children (3–26 yrs old)	Semi-structured interviews used to develop a CI (parents' and children's reports), EDSS	Daughters coped better than sons. Healthy mothers and daughters coped better versus healthy fathers and sons	Medium (9/12)
46	Examine children's perception of MS	Qualitative	21 children (7–14 yrs), parents' MS duration 1.5–7.5 yrs (5.83 average)	Semi-structured interviews (children's reports)	Few children had accurate information for MS Most frequent causal beliefs: fate, chance, contagion, congenital. No children believed that parents' MS would get worse	Medium (7/10)
40	Children's experiences of life with a parent with MS	Qualitative	22 children	Interviews on how life was, is and will be	Hopeful–realistic attitude Ideas for reducing barriers Categories of oppression usually lay outside the family	Poor (4/10)
43	Investigate the relationship of fatigue and functional status of mothers with MS to their perception of physical affection with their children	Cross-sectional and qualitative	35 mothers with relapsing-remitting MS (29–46 yrs, able to walk) and 1 child of each mother (6–20 yrs)	EDSS, Fatigue Severity Scale, Maternal Support Inventory, Semi-structured interviews (children's and mothers' experience with MS and how exacerbation and fatigue were managed)	Functional status and fatigue were not significant predictors of physical affection during an exacerbation. Mothers underestimated changes in their physical affection. Interviews elicited anxiety and fear children felt due to exacerbations	Medium (7/12)

39	Investigate parent and family factors associated with children's mental health problems	Cross-sectional	174 family with children ages 7–17 yrs	PSS, Personal Resources Questionnaire CES-D SIP, Minimal Record of Disability, APGAR, FACES-II,Economic Adequacy, Dyadic Adjustment Scale, ACBC (parents' reports)	Children who were not at risk of mental health problems tended to live in families who were more adaptable, had more adequate finances, and had more marital agreement.	Poor (6/12)
25	Investigate interaction patterns of mothers with MS and their daughters	Case–control study	31 mothers with notable impairment and their daughters (8–12 yrs) and 34 control dyads	Measurement of Social Status Scale, Videotapes of mothers and daughters, validity questionnaire	No differences between the two groups of mothers or the two groups of daughters	Good (11/12)
29	Investigate the reported quality of life in children with a parent with MS	Qualitative study	32 children (6–17 yrs old) Parents 30–47 yrs old, 24 of 28 parents in remission	Interview children on impaired parental health	Overall good quality of life. Limited knowledge of MS. Feelings of fear, anger and sadness	Medium (6/10)
31	How children with a parent with MS perceive family environment	Case–control study	33 children with a parent with MS (12–18 yrs) and 33 children with 'healthy' parents	Family Environment Scale (children's reports)	MS families: higher conflict, lower cohesion, lower intellectual–cultural orientation, lower organization, lower moral/religious emphasis	Good (10/12)
26	Investigate the development of body image on children with a parent with MS	Case–control study	124 children with a parent with MS (visible disability) 60 children with 'healthy' parents(7–11 yrs old)	Draw-A-Person test, Semantic Differential Body-Cathexis scale	Body image scores did not differ between groups. Body image distortion tended to be greater in girls with MS mothers than girls with MS fathers or boys with MS mother	Medium (9/12)
27	Investigate psychological characteristics of children of people with MS	Case–control study	60 children with a parent with moderate-severe stage MS, 221 children, control group	Rorschach test	Children with a parent with MS scored higher in: Body concerns Dysphoric feelings, Hostility, Constraint in interpersonal relations, Dependency needs	Good (10/12)

MS, Multiple sclerosis; EDSS, Expanded Standard Disability Status Scale; BDI, Beck Depression Inventory; CI, Coping Index; ACBC, Achenbach's Child, Behaviour Checklist; YSR, Youth Self-Report; FAD, Family Assessment Device; KI, Karnofsky Index; TAT, Thematic Apperception Test; SDQ, Strength and Difficulties Questionnaire; PSS, Perceived Stress Scale; SIP, Sickness Impact Profile.

assessment procedures between study and control groups. For example, in one study,[37] the control group completed the questionnaires in a classroom setting, whereas children with a parent with multiple sclerosis completed the questionnaire at home. In another,[31] the control group of children with 'healthy' parents was recruited from a religious school, whereas children with a parent with multiple sclerosis were recruited from the Multiple Sclerosis Society of Canada. Second, in some cases, the questionnaires were mailed to children to be completed at home, so the researchers did not have control over parental influence. Third, some studies used projective measures, such as the Rorschach test,[27] Draw-a-Person test[26] and Thematic Apperception Test,[38] to measure psychopathology. These measures have low reliability and validity.

Overall, of the 16 studies conducted to explore children's adjustment to their parents' multiple sclerosis, 3 (1 poor, 1 good and 1 medium quality) found no impact on children, whereas the remaining 13 showed that these children faced a number of psychosocial difficulties.

Part 2: Potential moderating factors influencing child adjustment

The nature of children's distress may depend on other factors related to the child, parent's illness characteristics or family environment. Eleven studies explored factors that might moderate children's adjustment (Table 3).

Parental negative emotions

Based on both parent and child self-report for psychological well-being and behavioural problems, four studies, one good, two medium and one poor quality showed that depression in a parent was linked with poorer child adjustment.[34–36,38] In particular, the higher the parental depression levels the higher the parental report of psychosocial problems in the children.[35,36] Furthermore, other negative states such as parent's fatigue, confusion and tension were found to be associated with parent reports of children's peer problems.[35]

Illness characteristics

Some studies suggest that illness severity and stage play a negative role in children's adjustment. A good-quality study showed parental functional impairment and unpredictability of the parent's multiple sclerosis were related to poorer adjustment in children.[37] Illness severity was also found to be associated with emotional distress in children in a good-quality study.[34] A medium-quality study reported that illness exacerbation was associated with mothers being less affectionate, which served to trigger anxiety and fear in the children.[43]

Family environment

Family environment can act either as a protective or a risk factor in children's adjustment to parental multiple sclerosis. A good-quality study found that family dysfunction was associated with child maladjustment.[34] Two good studies found that higher family responsibilities and less choice in helping may be related to poorer adjustment in children.[37,41] Finally, the better the healthy partner was coping, the better their children were coping according to a medium-quality study.[44]

Gender of children and parent with multiple sclerosis

Research has also found that the gender of the child and the parent with multiple sclerosis also influences children's coping. In a medium-quality study, daughters coped better than sons. Moreover, healthy mothers and daughters coped better than healthy fathers and sons.[45] There are also findings from a medium-quality study showing that the children of mothers (and not fathers) with multiple sclerosis presented greater problems.[36]

Child factors

Children's resources influenced the way they adjusted to parental multiple sclerosis. A medium-quality study found that better adjustment was related to children's higher levels of social support, lower feeling of stress, increased use of problem-solving strategies to cope and avoidance of

Table 3 Factors associated with children's maladjustment

Factors	Specific aspects	Quality of the study	Design	Ref.
Parental negative emotions	Depression	Good	Case–control	34
		Medium	Cross-sectional	35
		Poor	Cross-sectional and qualitative	38
		Good	Cross-sectional	36
	Fatigue, confusion, tension	Medium	Cross-sectional	35
Illness characteristics	Functional impairment	Good	Case–control	37
	Illness severity	Good	Case–control	34
	Illness exacerbations	Medium	Cross-sectional and qualitative	43
Family environment	Higher family responsibilities and less choice in helping	Good	Qualitative	41
		Good	Case–control	37
	Family dysfunction	Good	Case–control	34
	–less adaptability	Poor	Cross-sectional	39
	–less marital agreement			
	'healthy' parent's poor coping	Medium	Cross-sectional and qualitative	44
Gender	Sons with a mother with MS	Medium	Cross-sectional and qualitative	45
Children factors	Limited knowledge about MS	Medium	Qualitative	29
		Medium	Qualitative	46
	Lower social support, higher stress appraisal	Good	Case–control	37

wishful thinking and denial.[37] Furthermore, a good qualitative study identified several different strategies that children used to help them cope. These included expressing emotion, distraction, seeking social support and making time for recreation.[41] According to two medium quality qualitative studies children's knowledge of multiple sclerosis may have played a role in their adjustment.[29,46]

Shortcomings of these studies should be taken into consideration. The methodology of some of these studies was unclear. For example the mix of quantitative and qualitative methods in some studies was vague and the presentation of the results was confusing.[43] Whereas a longitudinal design would have been more appropriate to answer questions related to factors influencing adjustment over time, all studies reviewed in this paper were cross-sectional. Another limitation of some studies is the diverse sample characteristics (e.g. diverse illness characteristics, time since onset and diagnosis), which makes it difficult to draw conclusions about factors that may have played a role on children's adjustment. Finally, in most studies medical staff referred patients to the study; therefore the selection of the participants may not have been representative of the general population of families with a parent with multiple sclerosis.

Discussion

The review found good evidence for a negative impact on children's well-being and especially on adolescents in the context of a parent with multiple sclerosis. This is consistent with the findings of reviews of children with a parent with physical disability.[3,47] Specifically, the illness was found to have a negative impact on social relationships; children had less cultural and intellectual activities, reported less family cohesion and more family conflicts. Also children reported being anxious about their parent's health and worried about their sense of obligation and their own future. The review also identified further factors associated with poor adjustment. These factors included parental negative emotions, increased illness severity, family dysfunction, lack of knowledge about multiple sclerosis and lack of social support.

The review also highlighted that some studies included in this review were methodologically weak and inadequate to provide robust evidence of impact of multiple sclerosis and possible factors influencing adjustment on children.

This review compares the findings that have been conducted on school-age children to adolescents and found that the studies on adolescents showed a higher risk for maladjustment. This mirrors the findings of other studies on children's adjustment to parental physical illness.[2,5,6] Further research is needed, however, to confirm this developmental effect. In the current review, only two studies investigated school-age children exclusively. Specifically, one study found no difference on mother (with multiple sclerosis)–daughter interaction during work and play tasks compared with 'healthy' mothers and daughters.[25] However, the mothers with multiple sclerosis in this study were not severely impaired, which might limit the findings. Moreover, the fact that mothers with multiple sclerosis interact with their daughters in play and work tasks the same way as 'healthy' mothers and daughters does not preclude the development of negative feelings and social problems in these children. The other study on school-age children found no statistically significant differences on body image distortion on children with a parent with multiple sclerosis compared with children with a 'healthy' parent.[26] Again, this does not preclude the existence of other psychosocial problems in these children. More research is needed to focus on school-age children in order to investigate more clearly the psychosocial aspects of children's lives that might be affected by parental illness.

Consistent with another review on the impact of different parental illnesses on children,[2] this review showed that the impact of parental illness depends upon a number of factors, including child age, gender, individual and family coping styles. This review also showed that children's misconceptions about multiple sclerosis, greater feeling of stress and poor social support were associated with children's distress and poor adjustment. Moreover, more severe symptoms and impaired function in parents with multiple sclerosis may be connected to more psychosocial problems for the children. Also, an adaptable family environment with adequate finances and with a good relationship between the parents appeared to protect children from developing psychosocial problems.

Parental depression was also found to moderate the impact of parental multiple sclerosis on child's adjustment. Parents with increased levels of depression were more likely to perceive increased psychosocial problems in their children, particularly emotional distress. It was also reported that irrespective of the gender of the ill parent in the families with parental multiple sclerosis, the more depressed the mother (and not the father), the greater the problems in the children. These findings are consistent with the broader literature on maternal depression, which has consistently shown an association between maternal depression and increased risk for emotional distress among children.[48]

This review has identified several gaps and methodological shortcomings in the literature on child adjustment to having a parent with multiple sclerosis. For example, most studies have not systematically investigated the specific factors that influence adjustment within a clear theoretical or developmental framework. Moreover, the cross-sectional nature of the studies reviewed makes it difficult to establish whether any problems children report are short lived and reflect responses to acute changes in the illness and family environment or whether they show continuity over time. Longitudinal studies that measure family factors, illness characteristics, individual characteristics and child distress at repeated points in time are needed to investigate the impact of familial, illness and individual factors on the adjustment process. Moreover, case-control studies should give more attention to using the same assessment procedures for both case and control groups. Finally, most of the studies have failed to separate older and younger children in their analysis and it is likely that developmental differences confound their results.

There are findings in the broader literature which have consistently found an association between maternal depression and increased risk for emotional distress among children. People with multiple sclerosis have an increased risk of developing depression[17] and multiple sclerosis is more common in women than men.[12] Therefore, the findings of maladjustment of children with a parent with multiple sclerosis may be a result of women with multiple sclerosis developing depression which then impacts on their children. The specific impact of maternal depression and maternal multiple sclerosis and child outcome should be addressed more clearly in future studies.

We need to find out more about individual differences across families and across children. Increased knowledge of factors related to risk and resilience and child adjustment will help researchers and health professionals to design interventions and preventive methods to help children and families adapt better to parental multiple sclerosis. Demographic characteristics such as a child's age and gender, years of exposure to illness, child's conception before or after the onset of the illness, may play a role in children's adjustment and should be considered in future studies.

This systematic review has some limitations. There is a possibility for some papers to have been missed, particularly as the search algorithm was adapted and restricted. However, the thorough approach employed to identifying papers counters this to a large extent. Furthermore, studies on languages other than English were excluded.

Due to the paucity of studies conducted on children with a parent with multiple sclerosis, the inclusion criteria were wide; which meant that some studies included were methodologically weak and inadequate to provide robust evidence of the impact of multiple sclerosis and factors influencing adjustment on children. Finally, the findings of this systematic review, due to the lack of quantity and quality of research on this area, cannot provide strong evidence to allow definite conclusions in terms of the factors influencing children's adjustment and the effects of developmental stage on adjustment.

Possible clinical implications

Families with a parent with multiple sclerosis have been shown to have more conflict and less cohesion.[31] At the same time, families who are more adaptable and have more marital agreement can protect children from developing high levels of psychological distress.[34,39] It would be useful for psychosocial interventions to focus not only on the children, but to include other family members as well and reinforce those protective factors. For example, family interventions might include techniques to support the process of adjustment to new challenges and family roles as well as couple counselling.

Multiple sclerosis might have a negative impact on children's social life and recreational activities.[28,31] Also social support has been shown to be associated with better adjustment.[37] In order to facilitate support creation and better adjustment, it might be useful to design group or individual interventions aiming to help children to build up their social skills or interventions aiming to increase network size or perceived support.

The review highlights that children need more information around multiple sclerosis[29,46] and that they are worried about a sense of obligation towards their parents and additional roles and responsibilities they have to undertake.[32,37,41] These findings suggest that it would be helpful for health professionals to give children age-appropriate information and an opportunity to ask questions about the disease that they may not be willing to ask a parent. This information could not only focus on multiple sclerosis facts; but also include what children can and cannot do to help their parent.

There is only one study that evaluated the effectiveness of an intervention for children with a parent with multiple sclerosis. The intervention was a six-day camp programme involving both recreational activities and eight group sessions providing education about multiple sclerosis. The programme included providing children with strategies to identify a range of different feelings, as well as giving them cognitive restructuring, problem-solving strategies, and emotion-focused coping skills.[49] Children who attended the intensive residential psychosocial intervention reported significant decreases in distress, stress, caregiving compulsion and activity restrictions and increased social support and knowledge of multiple sclerosis. Parents perceived that the increase in the child's knowledge of multiple sclerosis was associated with an increase in his or her supportiveness. However the study was limited by the small sample size ($n = 20$) and the lack of control group.

Clinical messages

- Good-quality studies on psychosocial effects of parental multiple sclerosis on children are scarce.
- There is good evidence that parental multiple sclerosis has a negative psychosocial impact on children, especially adolescents.
- There is some evidence to suggest that family and individual factors are potentially associated with children's adjustment to their parent's multiple sclerosis.

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Competing interests
None declared.

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