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The Impact of Multiple Sclerosis on Parenting: A Mixed-Method Systematic Review

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Abstract

Purpose MS symptoms can interfere with daily functioning, making parental responsibilities more challenging. This review synthesises quantitative, qualitative, and mixed-method evidence to determine how MS affects parenting capabilities and experiences.

Methods and Materials This review follows PRISMA and JBI guidelines. Systematic searches were conducted across Academic Search Complete, CINAHL, PsychINFO, PubMed, and Scopus databases, yielding 1,792 results. These were screened using SPIDER framework criteria to identify studies examining parenting measures and experiences amongst parents with MS.

Results This review included 22 studies, eleven quantitative, nine qualitative, and two mixed-method studies. Overall, 2,466 parents with MS participated in the studies included. Synthesised findings indicated that MS significantly impacts parenting, predominantly negatively. Four main themes emerged from the synthesis: Risk and protective factors related to parenting with MS; Impact of parental MS on parenting activities and daily family life; Emotional impact of MS on parents and views of relationships within the family; Managing and coping as a parent with MS.

Conclusion Many parents with MS encounter substantial daily challenges due to fatigue, limited mobility, and cognitive difficulties. Several potentially helpful supports were identified for parents with MS, including mental health supports, social support networks, and assistance with family communication about MS diagnosis.

Keywords: Multiple Sclerosis, parenting, parental Multiple Sclerosis, systematic review.

Introduction

The global average age of Multiple Sclerosis (MS) diagnosis is 33 years old (MSIF, 2020), which is an age where many people may be considering parenthood or actively raising children. Common symptoms of MS include bladder and bowel dysfunction (prevalence: 74%), fatigue (66%), sleep disturbances (59%), spasticity (51%), and impaired mobility (38%; Gustavsen et al., 2021) as well as impaired vision (34.6%; Jasse et al., 2013), and cognition (Benedict et al., 2020). These symptoms, when coupled with the frequently experienced challenges associated with being a parent, may make the parenting role more difficult.

Mental health issues, particularly depression and anxiety, are found to be more prevalent in those with MS compared to a matched general population, with the prevalence of depression reported as 31.7% vs. 20.5% and anxiety reported as 35.6% vs. 29.6% (Marrie et al., 2013). A more recent systematic review of the prevalence of depression and anxiety in MS reported the prevalence of depression as 30.5%, and anxiety as 22.1% (Boeschoten et al., 2017). Mental health issues add to challenges of everyday life, and have been found to impact parenting in non-MS populations. Yang & Williams (2021) reported that parents with higher depressive symptom scores had significantly lower scores of parental self-efficacy. Depressive symptoms have been found to predict a variety of parenting behaviours linked to problems in child development (Dix & Meunier, 2009).

Other symptoms of MS have been reported to impact parenting, including pain, fatigue, and cognitive impairment. Pain experienced by people with MS, can often be chronic, lasting for periods longer than 12 weeks. In a study conducted on parenting with chronic pain (Wilson & Fales, 2015), it was found that parents with chronic pain (CP) reported reduced

parental involvement with their children, inconsistent discipline, increased impatience, guilt and self-disappointment, and reduced physical activity with children. Only one parent with chronic pain (out of the 57 interviewed) reported no impact of CP on their parenting in these areas (Wilson & Fales, 2015). Fatigue has also been found to impact painting, and higher levels have been found to correlate with lower levels of parenting self-efficacy (PSE). Lower PSE was associated with lower parenting warmth and higher hostility (Chau & Giallo, 2014). Dunning & Giallo's study (2012) suggests that fatigue is associated with higher levels of parenting stress, lowered parenting satisfaction, and that fatigue may contribute to less enjoyment and pleasure within the parenting role. Cognitive impairment may also contribute to difficulties as a parent, for example, Deater-Deckard et al., (2009) found that mothers with poorer working memory reacted more negatively to children during a cooperative task than mothers with better working memory.

It is important to understand what factors or mechanisms underlie the parenting experience with MS, in order to enhance support for parents with MS and their families. The established impact of certain symptoms commonly associated with MS on parenting, such as poor mental health, fatigue, and pain further highlights the need to investigate the impact of MS on parenting.

Previous research on parental MS has mainly focused on the impact that it can have on children. Children of parents with MS have reported struggling with various aspects of parental MS, such as: lessened time to engage in leisure activities due to chores; mood changes in the parent with MS; a lack of information relating to the disease; and lessened engagement from the parent with MS in parenting and family activities (Mauseth & Hjälmhult, 2016). Findings regarding the long-term impact of MS on children are varied, with

some studies suggesting a negative impact on children's psychosocial adjustment, while others do not corroborate this finding (Haker et al., 2022). Bogosian et al. (2010) suggest that parental MS has a negative impact on children's social and familial relationships and their psychological well-being, and identify potential factors associated with poor adjustment; parental negative emotions; increased illness severity; family dysfunction; lack of knowledge about the illness; and lack of social support (Bogosian et al., 2010).

Existing research has provided some evidence of the impact MS has on the parenting role. A recent meta-synthesis conducted by Ghezelhesari et al (2024), explored motherhood needs in a cohort of mothers with MS. This study highlighted a need for improved support in all dimensions of the parenting role as a mother with MS, specifically psychotherapeutic supports, and increased information regarding the condition.

Dunne & Ryan (2024) recently conducted a systematic review focused on being a parent with a physical disability. Three of the eleven studies reviewed included parents with MS in their groups of mixed physical disabilities, without stratification by condition or disability. These studies reported parents' fears that they are not 'good enough', struggles with inaccessibility, and difficulties in accessing formal support. The studies also highlight parents' beliefs that added responsibilities meant that their children had grown up too fast, and that ill-health and fatigue are barriers to the parent-child relationship. The remaining included studies examined a range of other physical disabilities, and explored themes of stigma, inaccessibility, underrepresentation and support. Overall, the review points to the need for increased support for parents with both visible and invisible disabilities.

The present study aims to expand upon existing research, by including studies which

focus solely on parents with MS, and including both mothers and fathers. Previous reviews, have focused on only mothers with MS (Ghezelhesari et al., 2024), have included pwMS alongside other mixed cohorts (Dunne & Ryan, 2024), and have included only qualitative studies (Dunne & Ryan, 2024; Ghezelhesari et al., 2024). The current systematic review aims to synthesise all available evidence including quantitative, qualitative, and mixed method studies of the impact of MS on parenting, in order to answer the following research questions:

1. Does MS have an impact on parenting?
2. If so, how and in what ways is parenting impacted when a parent has MS?
3. If so, have any potential supports for parents with MS been identified?

Methods

Registration and Approach

This review followed the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidelines (Page et al., 2021). The review was registered with the International Prospective Register of Systematic Reviews (PROSPERO, ID: CRD42024569061). The Johanna Briggs Institute (JBI) guidance for mixed-method systematic reviews was followed during review question formation, data synthesis and extraction, and reporting results (Aromataris et al., 2024).

Inclusion and Exclusion Criteria

The following inclusion/ exclusion criteria were determined using the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) Framework (Cooke et al., 2012). Searches were carried out on the 24th of August 2024.

Inclusion

1. Samples of parents who have a diagnosis of multiple sclerosis.
2. Any published quantitative, qualitative or mixed-method study exploring the relationship between parenting and MS.
3. Studies which explore the experiences of parents with MS, or factors associated with MS which impact parents and parenting.
4. Peer reviewed studies.
5. Published in English.
6. No date-based inclusion criteria.

Exclusion

1. Samples of only children or partners of a parent with MS.
2. Samples of parents who were diagnosed with MS after their children had turned 18.
3. Systematic reviews, meta-analyses, protocols, theoretical work, conference papers, editorials, opinion pieces, dissertations, and grey literature.

Search Strategy

Electronic searches of the following databases were carried out: Academic Search Complete, CINAHL, PsychINFO, PubMed, Scopus. Additionally, forward and backward citation searching was carried out to identify additional relevant studies. The concepts searched were (a) multiple sclerosis and (b) parenting. Where possible, MeSH or equivalent subject indexing was used for the concepts of MS and parenting. An example of the search strategy used in PubMed can be seen in Figure 1. The search strategies used in the other databases were based on this strategy and adapted as needed. All search strategies are

available to view in supplementary materials.

Figure 1

Example of Search Strategy Used in PubMed

((("multiple sclerosis"[MeSH Major Topic]) OR ("multiple sclerosis"[Title/Abstract])) AND (("parenting" OR "child rearing"[MeSH Major Topic]) OR ("parental"[Title/Abstract] OR "parent"[Title/Abstract] OR "parents"[Title/Abstract] OR "parenting"[Title/Abstract] OR "child rearing"[Title/Abstract] OR "child raising"[Title/Abstract] OR "motherhood"[Title/Abstract] OR "parenthood"[Title/Abstract] OR "fatherhood"[Title/Abstract]))

Screening and Selection Process

Studies retrieved from the database searches were imported to the citation manager Mendeley (Reiswig, 2010), where duplicates were identified and removed. The remaining records were uploaded to the systematic review software Rayaan (Ouzzani et al., 2016), where title and abstract screening took place. Two reviewers (ESD and FOK) independently screened 100% of the title and abstracts of each of the records based on the eligibility criteria. Reviewers resolved any discrepancies through discussion until a consensus was met. All records which met criteria underwent full-text screening, during which the final inclusion/ exclusion decisions were made. Due to time restrictions, one reviewer (ESD) screened 100% of the full-text articles, and the second reviewer (FOK) screened a random

40%, after which any discrepancies were resolved through discussion.

Data Extraction and Synthesis

Data was extracted by one reviewer (ESD) and checked by the second reviewer (FOK). A data extraction form created on Excel was used to systematically extract the following data: title, authors, publication date, journal, country, sample size, methodological approach (design and data collection method), and findings that were relevant to the research questions of whether and if so in what way MS impacts parenting.

Data synthesis followed a convergent integrated approach, as detailed in the JBI methodology for mixed methods systematic reviews (Aromataris et al., 2024). This approach was chosen over a convergent segregated one as there are multiple research questions which can each be addressed by both quantitative and qualitative research designs. Quantitative data was converted into 'qualitized data'. This involved transformation of quantitative numerical results into textual descriptions or narrative interpretations (including the quantitative component of mixed methods studies). The transformed quantitative data was then combined with the qualitative data, each finding was then categorised and pooled together based on similarity in meaning to produce a set of integrated findings and themes. Due to the heterogeneous nature of the study designs included in this review, no statistical comparisons were made.

Quality and Risk of Bias Assessment

The methodological quality of studies was assessed using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018), which can be used across qualitative, quantitative, and mixed-methods studies. There are five appraisal categories pertaining to different

methodological approaches: qualitative research, randomised controlled trials, non randomised studies, quantitative descriptive studies, and mixed methods studies. Each category consists of five items answered with “yes”, ”no” or “can’t tell”. The sections created for qualitative research, quantitative descriptive research, and mixed-method research were used. Quality appraisal was carried out by both reviewers (ESD and FOK), using the MMAT assessment tool for 100% of included studies. Any disagreements regarding the scoring of articles were resolved through discussion until inter-rater agreement was reached.

Results

Characteristics of Included Studies and Participants

In total, 1,790 studies were retrieved from database and manual searches. A total of 22 studies met inclusion criteria and were systematically reviewed. The full screening process is detailed in Figure 2.

Main results and characteristics of each study are summarised in Table 1. Of the twenty two articles reviewed, eleven (50%) were quantitative, nine (40.9%) were qualitative, and two (9.1%) were mixed-method studies. The studies were conducted in: USA (N=7), Italy (N=5), Australia (N=3), Canada (N=1), Finland (N=1), Germany (N=1), Iran (N=1), Netherlands (N=1), New Zealand (N=1), and Switzerland (N=1).

Sample sizes ranged from 4 participants (Shevil & Finlayson, 2006) to 1,089 (Twork et al., 2007). Overall, a total of 2,466 parents with MS participated in the studies included. Of these, 12 studies included mixed gender parents with MS, and 10 studies included only mothers with MS. 2,401 others also participated in the studies, these included: non-parents with MS, parents without MS, and family members of parents with MS (partners and children).

Figure 2

Prisma Flowchart of the Screening Process

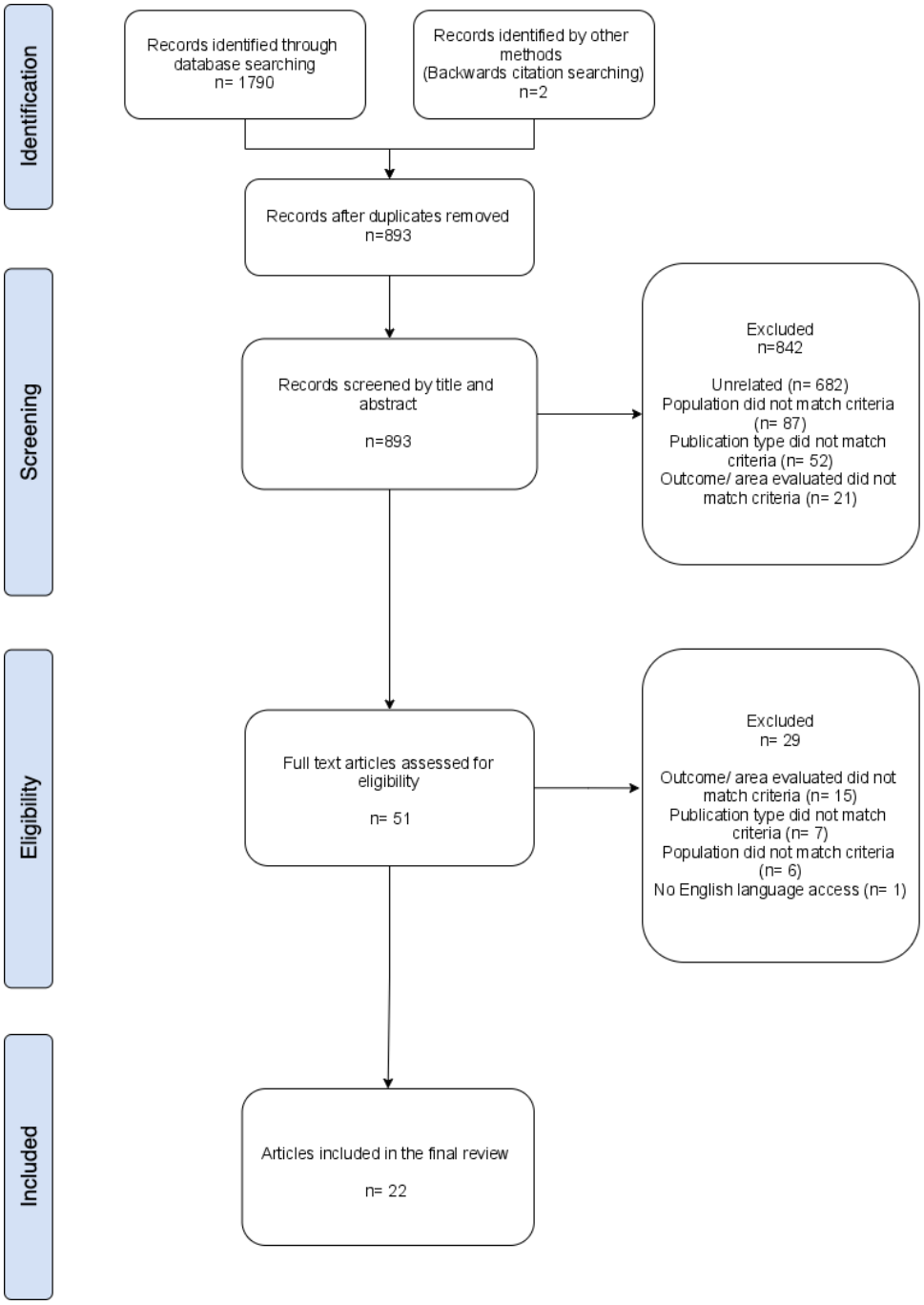


Table 1.

Characteristics of Included Studies

Author	Country	Methodology	Measures	Sample	Relevant findings	Quality rating (MMAT)
Bostrom & Nilsagard, 2016	Finland	Qualitative	/	9 (PwMS), 14 (family members).	Communication with family and others surrounding MS was difficult for PwMS; difficult to answer children's questions regarding MS; misunderstandings both within and outside of family. Feelings of guilt expressed by PwMS regarding increased chores for children. Management of MS by making practical adjustments to everyday objects. Benefits of parental MS; having a stay at home parent; increased responsibility in children. Suggestions for better support from health care providers: family counselling; guidance on how to support children; information	****

					sessions for family.	
Crist, 1993	USA	Quantitative	Mother-daughter interaction tasks, MVQ	31 (MwMS), 34 (Mothers w/o MS), 65 (children).	No significant difference between MwMS and mothers w/o MS for receptiveness, directiveness, or disuasiveness in interactions with their children.	***
Deatrick et al., 1998	USA	Mixed- method	EDSS, FSS, MSI	35 (PwMS), 35 (children).	MwMS perceived that they were significantly less affectionate with children during an exacerbation of symptoms compared to when stable. MwMS underestimated their difference in affection in comparison with their children's perceptions. Qualitative findings: Adapting to fatigue & exacerbations; Struggles associated with fatigue & exacerbations; Affection with children impacted by exacerbations.	****
De Ceuninck van Cappelle et al., 2016	Netherlands	Qualitative	/	7 (PwMS), 3 (non-PwMS)	Capacity for housekeeping and child care lessened. Struggles with asking for or accepting help. Attitudes of others towards their illness can be damaging. Possible negative impact of parental MS on family.	****

Ehrensperger et al., 2008	Switzerland	Quantitative	TAP, RAVLT, 7/24 Spatial Recall Test, PTS, Vocabulary test, KEDSS, BDI	44 (PwMS), 108 (family members).	PwMS coping abilities correlated with partner's coping (r=0.58; p<0.01), and children's coping (r=0.30; P=0.06). PwMS had higher depression scores (mean=11.3, SD=7.9, range 0-34) than healthy partners (mean=4.8, SD=3.9, range 0-14). Depression scores of PwMS significantly positively correlated with EDSS (physical impairment) scores (r=0.49; P<0.01). Significant predictors of coping capacities of PwMS: BDI scores, z scores of divided attention performance, z-scores of estimated premorbid verbal intelligence.	****
Farber et al., 2015	USA	Quantitative	RSPWB, MOSSSS, Emotional & physical subscales of SF-36, PPS	111 (MwMS)	MwMS showed slightly less limitation in role participation due to emotional versus physical health reasons (45.59 vs. 42.31), *p*=.03; both were significantly lower than the general population scores of 50 (both *p*s< .001). MwMS were not significantly less satisfied with parental participation than the general population(4.21 vs 4.31), t(164)=1.26, p = .21. Social support is significantly related to parental role participation and maternal satisfaction.	*****

Graziano et al., 2020	Italy	Quantitative	CESD, PANAS, IMS	32 (MwMS), 42 (non-MwMS)	MwMS had significantly higher depressive symptom scores than women with MS without children. The relationship between identity satisfaction and depressive symptoms was stronger for mothers than non-mothers (B=-026, $p<0.05$). Relationship between identity satisfaction and affective well being was stronger for mothers than non-mothers (B=0.28, $p<0.05$).	***
Haynes-Lawrence & West, 2018	USA	Qualitative	/	181 (PwMS)	Fatigue: “It greatly affects my parenting, more than any other aspect of my life I feel.” Fatigue limited the ability to partake in family activities, to maintain standards of behaviour for children, and impacted patience and mood. Feelings of guilt expressed due to impacted parenting. Descriptions of how parents manage their fatigue: caffeine, medication, planned rest times, organisation; spoon theory.	****
Messmer Uccelli & Ponzio, 2018	Italy	Quantitative	PDDS, PSOC, MSPSS, COPE, SF-12,	80 (PwMS), 80 (Parents w/o MS)	No significant differences between parents with and without MS for parenting sense of competence (PSOC), parenting efficacy, parenting satisfaction.	****

			HADS		Mental and physical health related QOL were independent predictors of PSOC.	
Messmer Uccelli et al., 2019	Italy	Quantitative	PSOC, HADS, Brief COPE, SF-12, MSPSS, EDSS	285 (PwMS)	For PwMS, PSOC was negatively related to anxiety (p=0.012), depression (p=0.001), and dysfunctional coping (p=0.005), as well as older parent age (p=0.002).	*****
Pakenham et al., 2012	Australia	Qualitative	/	145 (PwMS), 91 (partners)	MS limited ability to partake in physical activities with children. Transporting children was identified as an issue for PwMS. Day-to-day difficulties arose from fatigue and resulting lack of patience. Need for help with housework due to symptoms of MS; feelings of guilt when the burden of housework fell to children; difficulties in enlisting help from children. Feelings of guilt expressed due to lessened capability for family activities. Need for practical assistance (budgeting, bills, job searching).	****

Parton et al., 2017a	Australia	Qualitative	/	20 (MwMS)	Feelings of having failed at mothering; emotional distress expressed. Ability to be physically active with children mainly impacted by fatigue and limited mobility. Fears expressed that children's wellbeing may be damaged through aspects of parental MS; guilt about risk of passing MS on to children. Feelings of guilt due to impacted parenting. Lack of understanding from others; judgement; misperceptions. Feelings of losing independence when receiving help from others; difficulties in asking for help. Parents viewed their children as a source of motivation for looking after their own health.	Parton et al., 2017a
Parton et al., 2017b	Australia	Qualitative	/	20 (MwMS)	Sacrifices of own needs to prioritise parenting activities. Feelings of letting children down; Frequent comparison of their own parenting/ household capabilities to those of mothers without MS. Management of MS: organisation; prioritisation of tasks; self-care; time away from mothering. Fears expressed that children's wellbeing may be impacted through	****

					aspects of parental MS. Feelings of having failed as a mother expressed. Limited ability for maintaining standards of good behaviour for children. Benefits of parental MS: PwMS felt that their children are more compassionate and understanding, and have greater independence.	
Payne & McPherson, 2010	New Zealand	Qualitative	/	9 (MwMS)	Breastfeeding perceived to worsen MS fatigue. Importance of support from family and friends. Managing fatigue: organisation; pre-planning. MS compromised capacity to carry out some parenting activities.	****
Podda et al., 2022	Italy	Quantitative	HADS, Brief Cope, MSPSS	285 (PwMS)	Anxiety levels in PwMS correlated with their level of disability (OR, 1.18; P=.033), dysfunctional coping strategies (OR, 4.07; P<.001) and lower perceived social support (OR, 0.69; P=.014). Depression levels in PwMS correlated with their level of disability (OR, = 1.38; P < .001), emotion-focused (OR, 0.67; P = .031) and dysfunctional (OR, 2.34; P < .001) coping strategies, and lower	*****

					perceived social support (OR, 0.73; P = .040).	
Pour & Pourakbaran, 2017	Iran	Quantitative	PSEQ, BAI, Mindfulness questionnaire	105 (MwMS)	Mindfulness components of judgement and non-reactiveness correlated with less anxiety in MwMS. Mindfulness components of action with awareness, judgement and non-reactiveness correlated with increased parental self-efficacy in MwMS.	***
Razaz et al., 2016	Canada	Quantitative	/	360 (PwMS), 1207 (Parents w/o MS)	PwMS had higher rates of peripartum depression compared with parents in the reference cohort (25.8% vs 18.5%, p value 0.004). The rate of peripartum depression was 2.68 times higher (95% CI: 1.68–4.29) among FwMS as compared with fathers without MS. The rate of peripartum depression was 28% higher (95% CI: 0.99–1.65) among MwMS as compared with mothers without MS.	*****
Shevil & Finlayson, 2006	USA	Qualitative	/	3 (PwMS), 1 (non-PwMS)	Cognitive symptoms of MS made communication with children difficult. Misunderstandings arose from children and partners' misinterpretation of behaviour caused by cognitive changes/ difficulties.	***

Twork et al., 2007	Germany	Quantitative	FKV-LIS, MSQOL-54, EDSS	482 (PwMS), 607 (non-PwMS)	MwMS had higher 'social functioning' ($p=.03$) MwMS higher religiosity/ search for sense in life coping behaviour than non-mothers with MS ($p=.004$)	****
White et al., 2009a	USA	Mixed-Method	MPI, MFIS, SF-36	103 (MwMS), 91 (Mothers w/o MS), 68 (MwRA)	MwMS & RA had significantly more fatigue ($p<0.001$) and lower physical functioning ($p<.001$) than well mothers	****
White et al., 2009b	USA	Quantitative	MFIS, MOSS, CES-D, PDH, PS	103 (MwMS, 91 (Mothers w/o MS), 68 (MwRA)	Mothers with chronic illnesses (including MwMS) had significantly higher levels of depression, lower physical functioning, more sleep problems, and higher levels of fatigue. MwMS with more children, and who reported greater sleep problems reported more frequent and intense parenting daily hassles.	*****
Willson et al., 2017	Italy	Qualitative	/	16 (MwMS)	Feelings of a loss of control over everyday life. Identity as a mother negatively impacted. Struggles with accepting aid; e.g. stair lift. Stigmatising attitudes and their impact on the parent-child relationship.	****

	Pushing themselves to maintain their own standards of parenting; becoming exhausted. Sense of loss and regret at aspects of parenting not experienced as fully due to MS; family trips etc. Environmental barriers which hinder access for physically disabled parents.

Note. Abbreviations used: BAI (Beck Anxiety Inventory), BDI (Beck Depression Inventory), CESD (Centre for Epidemiological Studies Depression), COPE (Coping Orientation to Problems Experienced), EDSS (Expanded Disability Status Scale), FKV-LIS (Freiburg Questionnaire on Coping with Illness), FSS (Fatigue Severity Scale), FWMS (Fathers with Multiple Sclerosis), HADS (Hospital Anxiety and Depression Scale), IMS (Identity Motives Scale), KEDSS (Kurtzke Expanded Disability Status Scale), MFIS (Modified Fatigue Impact Scale), MOSS (Medical Outcomes Sleep Study), MOSSSS (Medical Outcome Study Social Support Survey), MPI (Multidimensional Pain Inventory), MSI (Maternal Support Inventory), MSPSS (Multidimensional Scale of Perceived Social Support), MSQOL (Multiple Sclerosis Quality of Life), MVQ (Maternal Validity Questionnaire), MWMS (Mothers with Multiple Sclerosis), MWRA (Mothers with Rheumatoid Arthritis), PANAS (Positive and Negative Affect Scale), PDDS (Patient Determined Disease Steps), PDH (Parenting Daily Hassles), PPS (Parental Participation

Scale), PS (Parenting Scale), PSEQ (Parental Self-Efficacy Questionnaire), PSOC (Parenting Sense of Competence), PTS (Performance Test System), PWMS (Parents with Multiple Sclerosis), QOL (Quality of Life), RAVLT (Rey Auditory Verbal Learning Test), RSPWB (Ryff Scales of Psychological Well Being), SF-12 (Short Form-12), SF-36 (Short Form-12,36), TAP (Testbatterie zur Aufmerksamkeitsprüfung).

Quality and Risk of Bias Assessment

The overall quality of the studies included in this review was adequate, with studies ranging from 100% (*****) to 60% (***). The breakdown of study quality ratings is as follows: 100% (N= 5); 80% (N= 13); and 60% (N= 4).

The quality of the eleven quantitative studies was adequate overall, ranging from 100% to 60%. All studies used appropriate sampling strategies and measures (criteria 1 and 3). Seven studies had quality issues regarding participant response rates (criteria 4), three of these had response rates of below 60% (Crist, 1993; Graziano et al., 2020; Twork et al., 2007), and four did not report response rates (Ehrensperger et al., 2008; Farber et al., 2015; Pour & Pourakbaran, 2017; Uccelli & Ponzio, 2018). Three studies had quality issues regarding sample demographics (criteria 2). Crist (1993) recruited participants through MS society groups, members of these groups could possibly have lesser disability, and as disability level was not reported, this study was marked ‘can’t tell’. Pour and Pourakbararan (2017) did not provide enough information to determine the representativeness of their sample, and Graziano et al.,’s (2020) study excluded participants with severe mental health and cognitive impairment.

The quality of the nine qualitative studies was adequate overall, ranging from 80% to 60%. All studies were based on appropriate approaches and used appropriate data collection methods (criteria 1 and 2). Eight studies had quality issues regarding consideration of context and researcher influence (criteria 3 and 4). Of these, four studies did not provide clear evidence of consideration for the influence of the researcher (Parton et al., 2017a; Payne & McPherson, 2010; Shevil & Finlayson, 2006; de Ceuninck van Capelle et al., 2016), and four did not provide enough information to determine if researcher influence was adequately considered (Bostrom & Nilsagard, 2016; Haynes-Lawrence & West, 2018; Pakenham et al., 2012; Parton et al., 2017b).

The quality of the two mixed-method studies was good overall, both studies had quality scores of 80%. Both studies provided rationale for the mixed-method approach, and integrated the qualitative and quantitative data adequately to answer the research questions (criteria 1 and two), although neither study discussed the limitations of mixed-method integration (criteria 3) (Deatrick et al., 1998; White et al., 2009a).

Does MS have an impact on parenting?

Overall, the synthesised findings from the quantitative, qualitative and mixed-method studies provide evidence that MS does have an impact on parenting. Of the 22 studies reviewed, 19 provided evidence indicating that multiple sclerosis (MS) has a considerable negative impact on parenting. Three studies did not find significant differences between parents with and without MS on measures of parent-child interactions (Crist, 1993), parenting satisfaction (Farber et al., 2015; Uccelli & Ponzio, 2018), parenting competence, and parenting efficacy (Uccelli & Ponzio, 2018).

How and in What Ways Parenting is Impacted by MS

Analysis of the included studies resulted in the identification of four overarching themes which detail how parenting is impacted by MS and the specific ways in which this impact is experienced: Risk and protective factors related to parenting with MS; Impact of parental MS on parenting activities and daily family life; Emotional impact of MS on parents and their views of relationships within the family; Managing and coping as a parent with MS.

Theme 1: Risk and Protective Factors Related to Parenting With MS

Several factors were identified which either positively or negatively impact people with MS capacity for parenting activities. Physical symptoms of MS reported to be an issue for parents included balance issues (Bostrom & Nilsagard, 2016), and limited mobility (Parton

et al., 2017a). Mothers with MS were found to have significantly lower levels of physical functioning than mothers without MS (White et al., 2009a; White et al., 2009b), and parents with MS viewed their bodies as 'unreliable' (Parton et al., 2017b). One mother summed up the physical impact of her MS on her everyday life: "in the physical capacity, it's changed how I see myself because I don't see myself as someone who can push through and do whatever I need to do…as a mum without MS, I felt a lot more capable as a person that I could manage whatever the day threw at me'' (Parton et al., 2017b).

The impact of cognitive symptoms of MS on parenting were mentioned in four studies (Ehrensperger et al., 2008; Haynes-Lawrence & West, 2018; Shevil & Finlayson, 2016; de Ceuninck van Capelle et al., 2016). Ehrensperger et al., (2008) found that the coping capacity of parents with MS can be predicted by divided attention performance scores. Many participants described their cognitive fatigue as 'brain fog', detailing difficulties in concentration, memory, and response time, all aspects involved in the parental role (Haynes-Lawrence & West, 2018). Parents with MS felt that fatigue and cognitive problems severely impacted their ability to care for children (de Ceuninck van Capelle et al., 2016). Cognitive symptoms were associated with issues with communicating effectively and maintaining attention, which were reported as a source of confusion and misunderstanding within the family (Shevil & Finlayson, 2006). Parents also felt that they were less able to provide discipline in a way that was respected by children. One mother explained that because it takes her longer to formulate what she wants to say, she often replies in what she perceives to be an unsatisfactory manner, "losing all credibility" (Shevil & Finlayson, 2016). Parents with MS sometimes felt that family members became upset when they had issues with maintaining attention in conversations (Shevil & Finlayson, 2006).

MS fatigue emerged as a prominent theme impacting parenting in five studies. One participant concisely described the impact fatigue has on parenting: "It greatly affects my parenting, more than any other aspect of my life I feel," (Haynes-Lawrence & West, 2018).

Mothers with MS were found to experience significantly more sleep problems and higher fatigue than mothers without MS (White et al., 2009a; White et al., 2009b), and mothers with MS who had more sleep problems reported more frequent and intense daily parenting hassles (White et al., 2009b). Fatigue was reported to lead to a lack of patience (Pakenham et al., 2012), and parents with MS perceived that they were more easily frustrated due to lessened patience and energy, "I yell more than I should because I am so exhausted." (Haynes-Lawrence & West, 2018). Some mothers with MS felt that frequent breast feedings and encountering complications while breastfeeding worsened their fatigue (Payne & McPherson, 2010).

Depression and anxiety were explored in six studies, and were found to negatively impact parenting sense of competence (Messmer Uccelli et al., 2019). Parents with MS had higher levels of depression than their partners (Ehrensperger et al., 2008), mothers with MS had higher depressive symptom scores than women with MS without children (Graziano et al., 2020), and mothers with MS had higher levels of depression than mothers without MS (White et al., 2009b). Peripartum depression was also higher amongst parents with MS than parents without MS, particularly in fathers with MS (Razaz et al., 2016). Physical impairment (Ehrensperger et al., 2008), disability level, emotion-focused coping, dysfunctional coping, and lower perceived social support (Podda et al., 2022) were found to correlate with higher levels of depression in parents with MS.

In mothers with MS, identity satisfaction was found to positively influence depression and affective well-being (Graziano et al., 2020). Pour & Pourakbaran (2017) explored mindfulness in the context of parenting with MS, and found that anxiety scores were lower in mothers who scored higher on their ability to be non-judgmental and non-reactive to their internal experiences, allowing them to explore their thoughts and inner feelings (Pour & Pourakbaran, 2017).

Higher perceived social support was related to higher parental role participation and

maternal satisfaction in mothers with MS (Farber et al., 2015). Higher mental and physical health-related quality of life correlated with higher parenting sense of competence (Messmer Uccelli & Ponzio, 2018), and negatively correlated with dysfunctional coping, and parent age (Messmer Uccelli et al., 2019). The mindfulness components of action with awareness, non-judgement, and non-reactiveness were found to correlate with higher parental self-efficacy (Pour & Pourakbaran, 2017).

Theme 2: Impact of parental MS on parenting activities and daily family life

Parents with MS reported issues with a range of tasks associated with the parenting role. In six studies, parents reported that their ability to partake in everyday activities with children was affected. Several symptoms of MS were reported to make physical and emotional interactions harder. Physical fatigue and limited mobility were reported to impact parents' capacity for engaging in physical games with children (Haynes-Lawrence & West, 2018; Pakenham et al., 2012; Parton et al., 2017a). Parents also reported that limited mobility meant that their ability to participate in family trips and activities was reduced, perhaps related to environmental barriers such as lack of accessibility (Willson et al., 2017). Parents in Willson et al.'s (2017) study reported that environmental barriers prevented them from entering their child's nursery school with them, with a mother with MS expressing that "it makes [her] feel really bad". Sensory symptoms were the reason that one mother with MS reported issues with reciprocating physical affection from her child when first diagnosed (Deatrick et al., 1998). Mothers with MS perceived themselves as significantly less affectionate with children during exacerbations, compared to times when they were stable (Deatrick et al., 1998).

MS was seen by some mothers as limiting their ability to interact with their children in the ways they deemed necessary for the development of healthy, well-adjusted future adults. For example, women spoke about their MS limiting the energy that they had available to shape their children through the setting of boundaries, shaping 'good' behaviour and role modelling values to their children, such as being 'clean' and a 'good worker' (Parton et al., 2017b).

Disciplining and maintaining standards of behaviour in children was identified as more difficult due to limited energy, with one parent with MS saying: "I tend to let behaviour issues slide because I don't have the strength to deal with it" (Haynes-Lawrence & West, 2018).

Other difficulties mentioned were issues with driving and transport due to limited mobility (Pakenham et al., 2012), and struggles with asking for and accepting help (de Ceuninck van Capelle et al., 2016) which was seen in some cases as due to a desire to avoid social judgement or burdening others (Parton et al., 2017a), or as a reluctance to make their illness seem more 'real' (de Ceuninck van Capelle et al., 2016). Household chores and tasks were also identified as an issue for parents due to limited energy, one mother reported that fatigue made it feel like "the smallest task is an excruciatingly hard thing to accomplish" (Haynes-Lawrence & West, 2018).

Three studies highlighted misunderstandings within the family as a result of the parents' MS. Adolescents sometimes expressed doubt that their parent's request for help with housework was explainable by their MS, asking questions like: "How can one be tired after a day at home?" (Bostrom & Nilsagard, 2016), or failed to grasp the extent of physical debilitation during exacerbations and recovery (Pakenham et al., 2012). One parent felt that family members attributed difficulties in attention and communication to disinterest rather than the cognitive symptoms of MS, and reported receiving negative comments from her children and husband which she felt were due to these misunderstandings (Shevil & Finlayson, 2016). Further misunderstandings which were described include balance, coordination and speech issues leading to the parent fearing that they may be perceived as drunk when in public (Parton et al., 2017a), and sometimes led to accusations of intoxication from others, which was reported to cause distress for both the parent and children (Bostrom & Nilsagard, 2016).

Theme 3: Emotional impact of MS on parents and their views of relationships within the family

Six studies explored the ways in which negotiating parenting with MS impacted

parents' emotional state, as well as dynamics within the family. Questions that children had about their parents' MS were sometimes difficult to answer, due to the complicated and unpredictable nature of the condition, and so communication with children about their MS was sometimes reported to be an emotionally-loaded task for parents (Bostrom & Nilsagard, 2016).

Guilt was a commonly expressed emotion among parents with MS. Often feelings of guilt were associated with increased housekeeping responsibilities placed on children (Bostrom & Nilsagard, 2016; Pakenham et al., 2012), and parents' perceptions that they were negatively affecting their child's wellbeing. Parents feared that they may pass their MS onto their children, or that witnessing their MS progression may cause their children distress, worry, or sadness (Parton et al., 2017b; Parton et al., 2017a). Parents also felt guilty that they had less capacity to interact with children through games and activities (Haynes-Lawrence & West, 2018; Pakenham et al., 2012; Parton et al., 2017b). Missing out on family activities was a source of loss and regret for parents, one parent asked the interviewer: "Do you know what it was like for me to be there in the wheelchair and watch my husband go on all the rides with the children? And me just sitting there... you have no idea what it felt like! But I had to do it!" (Willson et al., 2017).

Frequent thoughts and worries about what the future may hold for the parent with MS were thought to create tension in the family (Bostrom & Nilsagard, 2016). Parents reported that they felt there was a loss of 'harmony' in the family and reported feeling distant or isolated as a result, also reporting that it can be difficult to stay positive when family members are experiencing fear, grief, and confusion (de Ceuninck van Capelle et al., 2016).

The cultural expectations placed on mothers were a source of distress when MS got in the way of living up to their own, or others' expectations. Some participants with MS expressed concerns that they were a 'bad' mother because they were unable to carry out tasks in the way mothers are expected to, according to some cultural norms (Payne & McPherson, 2010). Mothers with MS compared themselves to mothers without MS, and to themselves before

diagnosis (Willson et al., 2017). Mothers felt as if they had 'failed' at mothering in the way they had envisioned (Parton et al., 2017b), which caused them psychological distress, reporting feeling "frustrated", "sadness", "very depressed" (Parton et al., 2017a). Both perceived and expressed stigmatising attitudes of others were reported to impact parents' relationships with children (Willson et al., 2017). Mothers worried that they might embarrass children due to physical disability such as using a crutch or a wheelchair, and one mother was asked by her child to stop attending parent teacher meetings to avoid her classmates seeing her wheelchair (Willson et al., 2017).

In three studies, parents with MS reported sacrificing their own energy and health in order to meet their personal expectations of parenting. Parents reported sacrificing time they would otherwise use for self-care and rest (Parton et al., 2017b), or drinking lots of caffeine despite knowing it is unhealthy (Haynes Lawrence & West, 2018). Prioritising parenting tasks ahead of their own management of MS made sense to parents who felt that the impact of their MS on their energy and mobility levels could prevent their child from experiencing a 'good' childhood (Parton et al., 2017b). Some parents reported that they pushed themselves beyond the limits of their energy levels, with one mother stating: "I've done everything that the other mothers have, I haven't done anything less! Even if I've forced myself, perhaps arriving home exhausted, but I've always taken him all over... I've always helped him to do whatever he needed to, I've never made him miss out on anything" (Willson et al., 2018).

Despite the challenges MS may add to the parenting role, parents in three studies (Bostrom & Nilsagard, 2016; Parton et al., 2017b; Parton et al., 2017a) discussed some benefits that they felt parental MS had on themselves and their children. They felt that their children had developed a greater sense of independence, and compassion due to the experience of having a parent with MS. Parents also discussed the motivation to look after their own health as mainly driven by their children (Parton et al., 2017a).

Theme 4: Managing and Coping With MS as a Parent

Parents managed their MS in different ways, and the process of developing and finding strategies that worked for everyday family life was described as “never-ending and time consuming” (Bostrom & Nilsagard, 2016).

Practical adaptations which parents had made were mentioned in three studies. Some parents used everyday items designed to lessen the impact of MS symptoms such as unbreakable drinking glasses and air conditioning to maintain a cool temperature indoors if heat exacerbated MS symptoms (Bostrom & Nilsagard, 2016). Some parents used sleep medications to help them manage their tiredness and sleep, at night time or at times when they had a few hours to rest in the day (Haynes-Lawrence & West, 2016).

Three studies included descriptions of how PwMS manage their fatigue, mainly through organisation and taking breaks when possible. Planning out activities in advance allowed parents to limit over-exerting themselves and possibly risking a relapse (Payne & McPherson, 2010). Prioritising activities such as cooking and cleaning, and creating a schedule in which those prioritized tasks could get done at a time when parents with MS had the most energy limited the impact of fatigue on daily parenting tasks (Parton et al., 2017b).

One study explored parents' use of the spoon theory to help with this process, in which one starts the day with a certain amount of spoons, which they use each time they perform a task (Haynes-Lawrence & West, 2016). A typical day as a parent with MS was described using the spoon theory: “I get up, to make breakfast is a spoon, to dress my daughter is a spoon, to dress myself is a spoon, to do our hair & brush teeth is a spoon, to load us in the car is a spoon, to unload is a spoon, like today we did a trip to the history museum with crafted [sic] & activities for 2 hours, that was 4 spoons at least. Then to load up & unload at home, 2 spoons. I am at 12 spoons before noon today. Won’t be doing much else today because I spent my spoons.” (Haynes-Lawrence & West, 2016)

Arranging time to nap or rest was important for parents with MS to conserve and regain energy (Haynes-Lawrence & West, 2016; Payne & McPherson, 2010). Some strategies for

creating pockets of time for rest were discussed by participants in Payne & McPherson's (2010) study; women would nap at the same times as their children, or arranged for their children to attend creches part-time throughout the week, as well as swapping play-dates with friends.

Coping was explored in two studies. Parents with MS' emotional and neuropsychological functions predicted their ability to cope with their MS. There was a correlation between the coping of the parent with MS, their partner, and their children's coping, suggesting that the whole family should be supported with adapting to the parent's MS (Ehrensperger et al., 2008). Another study found that mothers with MS utilise religiosity and search for sense in life coping strategies more than mothers without MS (Twork et al., 2007).

Several suggestions from parents regarding ways in which they could be better supported were highlighted, including family counselling, support related to how best to support children when living with MS as a parent, information sessions for family members (Bostrom & Nilsagard, 2016), help with budgeting and bills, and job search assistance (Pakenham et al., 2012).

Key themes and subthemes are detailed in a table which can be found in supplementary materials.

Discussion

This review aimed to address the intersection between Multiple Sclerosis and parenting.

The systematic review identified four overarching themes which illustrate the impact of MS on parenting. The first theme 'Risk and protective factors related to parenting with MS' details how MS symptoms were reported to interfere with the parenting role. Physical symptoms, including limited mobility, balance issues, and fatigue, significantly affected parents' ability to engage in daily parenting activities. Cognitive symptoms were discussed

by parents, noting how they can create communication difficulties within families, sometimes leading to tension and challenges in maintaining parental authority. Parents with MS experienced heightened levels of depression and anxiety compared to both their partners and parents without MS. Second, 'Impact of parental MS on parenting activities and daily family life' details the daily impact of MS as it manifests in struggles with participation in physical activities, performing routine childcare and household management tasks, and common misunderstandings.

The third theme 'Emotional impact of MS on parents and their views of relationships within the family' describes the emotional landscape experienced by parents with MS, and their perceptions of how their household is emotionally impacted. Parents experienced feelings of guilt about their perceived limitations and the perceived or feared impacts on their children. These emotional challenges were often intensified by cultural pressures, particularly for mothers, who reported feelings of distress due to perceived inadequacies. Family dynamics were affected by communication challenges and concerns about the future. Despite these challenges, some parents reported positive outcomes, including increased independence and compassion in their children. The final theme 'Managing and coping with MS as a parent', details the various adjustments made by parents to manage their condition while fulfilling their parenting roles. These strategies include practical adaptations to daily routines, careful energy management, and scheduling regular rest periods. Coping levels in parents with MS was found to correlate with coping of family members. Parents also discussed the ways in which they could be better supported, including family counselling and practical assistance.

The themes from the current review resonate with related research findings in the wider literature. MS symptoms have previously been found to hinder parents' ability to carry out typical daily activities and tasks and their engagement in the parent-child relationship

(Ghezelhesari et al., 2024; Dunne & Ryan, 2024). Parents with MS in the current review reported feelings of inadequacy when it came to caring for their children, which was also a prominent finding in previous studies that included pwMS (Dunne & Ryan, 2024; Ghezelhesari et al., 2024). Inaccessibility in public places arose as a significant barrier to parents engaging in family activities, which mirrors a main finding in Dunne & Ryan's (2024) exploration of parenting with physical disabilities. Previous research on the needs of mothers with MS has highlighted the importance of social and therapeutic support for pwMS, as well as the need for specific care and information from healthcare providers catered to pwMS, and the specific challenges that they may encounter (Ghezelhesari et al., 2024).

This review has identified some of the aspects of parenting that parents with MS struggle with the most, which could be potential target areas for practical support. The wide range of challenges experienced by parents with MS were explored mainly through qualitative studies, which provide valuable insight into the lived experiences of parents with MS. Parents discussed struggles associated with fatigue, which resulted in lessened energy for many parents to partake in parenting activities, such as family trips (Willson et al., 2017), games with children (Haynes-Lawrence & West, 2018; Pakenham et al., 2012; Parton et al., 2017a), and complete daily tasks and chores (Haynes-Lawrence & West, 2018). Practical supports such as assistance networks to aid with childcare or housework, as well as increased accessibility and rest areas in public areas commonly used by families, may provide respite for parents with MS.

Parents also discussed communication difficulties within the family, and the tensions that can arise on account of these difficulties (Bostrom & Nilsagard, 2016; Shevil & Finlayson, 2016). Parents reported that communication issues make it difficult to create boundaries and shape positive behaviours in children (Haynes-Lawrence & West, 2018; Parton et al., 2017b). Resources for parents as to how to communicate effectively, especially

regarding their MS diagnosis and symptoms, could be beneficial for the whole family, as previous research has suggested that the level of information children receive from parents regarding their MS can contribute to social difficulties and internalising behaviours (Cross & Rintel, 1999; Paliokosta, 2009).

This synthesis identified several other potential avenues for providing support to parents with MS. Higher perceived social support was related to higher maternal satisfaction and parental role participation (Farber et al., 2015), in line with previous research which has found social support to positively impact parenting self-efficacy (Fierloos et al., 2023), and mitigate negative effects of parental stress on children (Yıldız & Uzundağ, 2024). It was reported that mothers with MS had higher social functioning than non-mothers with MS (Twork et al., 2007), which further indicates the potential of increased social support for parents with MS, perhaps through informal or organisational peer-support networks. Digital support platforms specifically catered to parents and families with MS have potential for combining both practical guidance for adjustment to family life with MS, and accessible social support from those in similar situations both nationally and internationally. The charity MS-UK's 'Peer Pod' groups include a group catered for parents with MS, in which parents can attend drop-in support sessions to discuss concerns, experiences and advice with those who are in similar situations (MS-UK, 2025).

The importance of providing mental health supports for parents with MS is indicated by findings that depression scores are higher amongst parents with MS when compared to various different cohorts (Ehrensperger et al., 2008; Graziano et al., 2020; Razaz et al., 2016; White et al., 2009b), and that higher depression and anxiety, and lower mental-health related quality of life are correlated with lower parenting sense of competence in MS (Messmer Uccelli et al., 2019; Messmer Uccelli & Ponzio, 2018). There is a growing evidence base of effective mental health supports for people with MS. Russell et al., (2020) reviewed the

effectiveness of emotional wellness programs on mental health outcomes for people with MS, finding that they are effective in reducing stress, and moderately effective in reducing depression and anxiety. Cognitive Behavioural Therapy has also been established as an effective intervention in treating anxiety and depression in MS (Askey-Jones et al., 2013). A review of third-wave CBT interventions found that acceptance and commitment therapy (ACT), dialectical behaviour therapy (DBT), mindfulness-based stress reduction (MBSR) and mindfulness-based cognitive therapy (MBCT) are the most widely-implemented third-wave interventions for mental health in MS, although mixed findings indicated a need for further research to determine their efficacy (Zarotti et al., 2022). A review of mindfulness-based interventions (MBIs) for the mental wellbeing of people with MS by Simpson et al., (2020) found MBIs moderately effective for treating anxiety, depression, and stress. Future research could explore implementing such interventions for parents with MS.

The present systematic review is not free of limitations. Firstly, 10 of the included 22 studies had women and mothers-only samples, and the remaining 12 studies populations included both male and female parents with MS, with no men or father-only samples. However, this discrepancy may be expected due to the higher prevalence of MS in women than in men (Voskuhl, 2020). Secondly, the countries represented in this review are mainly 'WEIRD' (Western, Educated, Industrialised, Rich and Democratic), only one study falls outside of this category (Pour & Pourakbaran, 2017). Furthermore, LGBTQI+ couples are not explicitly represented, which limits our understanding of how people with MS experience the perceived stigma of parenting with MS, coupled with that of being parents as a LGBTQI+ couple. These underrepresented populations' experiences of parenting with MS should be further researched.

A further limitation of the current review is the exclusion of grey literature, which was considered outside of its scope. Including grey literature could have provided a more

comprehensive overview of the available evidence. Forms of grey literature such as MS forums and blogs may have provided additional insights into users first-hand descriptions of the experiences of parenting with MS, which may have added depth to the qualitative findings reviewed in this study.

Future research should focus on longitudinal studies which track the long-term impact of MS on the parenting role, examining how MS influences parenting across different stages of child development. Further research could more clearly investigate whether specific MS or parent factors are associated with greater or less impact on parenting, including characteristics of parents with MS, type of MS, age of parents and children, level of disability, age of diagnosis, etc. Future studies should also include diverse, underrepresented cohorts to explore a broader range of experiences and ensure any findings are applicable to a broader population. Additionally, research should aim to further explore and identify potential supports, and examine the effectiveness of social and mental health-based interventions for parents with MS.

Clinical Implications

This research highlights the importance of increased awareness among health care professionals regarding the impact MS has on parenting, and the need to include questions pertaining to the parental role at routine appointments. Our review also highlights the value of social support for parents with MS, as it was associated with higher maternal satisfaction and parental role participation. Our review also points to the need for formal support, such as information sessions, family counselling, and practical assistance regarding aspects of the parenting role which parents reported to struggle with most.

Conclusion

This systematic review of 22 mixed method studies comprised 2,466 parents with

MS, and 2,401 other participants (non-parents with MS, parents without MS, parents with rheumatoid arthritis and family members of parents with MS). The review demonstrates that MS significantly impacts both the parenting role and dynamics within the whole family. Synthesis established four key themes which feature the interplay between MS symptoms and family life, which manifests in challenges with communication with children and partners, limited capacity for participation in family activities and household tasks, and emotional distress. Synthesis also revealed the ways in which parents with MS adapt and cope with these challenges, including practical adaptations to daily routines and careful energy management. This research highlights the importance of comprehensive support which ensures that parents with MS are asked about the impact of MS on their parenting and family life during routine appointments. The study also points to the need for family counselling, specialised parenting guidance, practical support with daily tasks, as well as social and mental health-based supports, in order to help parents with MS maintain their parenting roles effectively while managing their condition.

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