

Intertwined like a double helix: A meta-synthesis of the qualitative literature examining the experiences of living with someone with multiple sclerosis

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Abstract

Background: Multiple sclerosis (MS) is a chronic serious condition of uncertain course and outcome. There is relatively little literature on the experiences of people who live with a person with MS. They inhabit a locus of care that spans caring for (a relational act) and caring about (a moral stance, addressing fairness, compassion and justice) the person with MS.

Methods: Using the theoretical lens of personhood, we undertook a scoping review and meta-synthesis of the qualitative literature on the experiences of people who live with a person with MS, focusing on the nature of, and constraints upon, caring.

Results: Of 330 articles, 49 were included in the review. We identified five themes. One of these—*seeking information and support*—reflects the political economy of care. Two are concerned with the moral domain of care: *caring as labour* and *living with uncertainty*. The final two themes—*changing identities* and *adapting to life with a person with MS*—point to the negotiation and reconstitution of personhood for both the person with MS and the people they live with.

Conclusion: People with MS are embedded in relational social networks of partners, family and friends, which are fundamental in the support of their personhood; the people who live with them are 'co-constituents of the patient's identity' assisting them to make sense of their world and self in times of disruption due to illness. Support services and health care professionals caring for people with MS are currently very much patient-centred; young people in particular report that their roles are elided in the health system's interaction with a parent with MS. There is a need to look beyond the person with MS and recognize the relational network of people who surround them and broaden their focus to encompass this network.

Patient and Public Involvement: Our research team includes four members with MS and two members with lived experience of living or working with people with MS. A

third person (not a team member) who lives with a partner with MS provided feedback on the paper.

KEYWORDS

care, chronic illness, lived experience, multiple sclerosis, personhood, qualitative

1 | BACKGROUND

Multiple sclerosis (MS) is a chronic demyelinating condition of the central nervous system, interfering with nerve impulses within the brain, spinal cord and optic nerves.¹ More than 2.2 million people are estimated to be affected worldwide.² Although MS can develop at any age, most people are diagnosed between the ages of 20 and 40 years, a life period where many have young families or are about to start a family.²

The clinical course of MS varies. The most common form is relapsing–remitting MS, in which periods of stability are interspersed with relapses.³ Primary progressive and secondary progressive forms of MS involve gradual worsening of symptoms over time. There is currently no known cure for MS, and the fundamental cause remains unknown.⁴ There are a number of treatment options, but which treatment best suits an individual is uncertain and requires complex decision-making for patients and families.⁴

Until recently, MS research has tended to focus on clinical outcomes, rather than experiential outcomes, and therefore has tended to elide the lives and experiences of people with MS.^{5–7} A chronic disease like MS impacts the whole family, but they have been the subject of little research.^{8–10} This points to a gap in the literature on the relational world of people with MS, and how this intersects with care.

In this paper, we are interested in people who live with people with MS. They inhabit a locus of care that spans Noddings' concepts of caring *for* (a relational act) and caring *about* (a moral stance, addressing fairness, compassion and justice).¹¹ Not all who live with a person with MS may formally understand their role as caring, but all share their lives with someone with a serious and long-term illness of uncertain course and outcome. Illnesses like these can lead to people feeling dislocated in biographical time, balancing time for self-directed projects and time taken up with the body and disease; the people they live with may play important roles in recognizing, supporting and being with the person, devoting time to the management of the body and disease.¹²

For people who live with a person with MS, the relational and moral perspectives of care can be viewed as addressing the recognition and sustaining of personhood.¹³ The purpose of this review was to (i) identify and chart current research knowledge on the experiences of people living with a person with MS and (ii) synthesize these results to explore the enactment of care, and its relation to personhood, by people living with a person with MS.

2 | METHODS

2.1 | Theoretical framework

Following Mauss,¹⁴ we define personhood as a person's human membership, roles or status in society attained through social relations. The lens of personhood is supplemented by a focus on the political economy of care, exploring how social, geographic and professional differentials are evinced in access to and distribution of biomedical knowledge, therapeutic interventions and social supports.^{15,16}

2.2 | Scoping review and meta-synthesis

We followed the scoping review methodology outlined by Arksey and O'Malley¹⁷ and enhanced by Levac et al.¹⁸ It provides a six-step framework for identifying the research question and relevant studies, selecting studies, charting the data, collating, summarizing and reporting results and consulting relevant stakeholders. Thematic analysis was then used to conduct a meta-synthesis of the included studies to provide a description of the experiences of people living with a person with multiple sclerosis (PwMS).¹⁹

2.3 | Research question

The research question guiding this review was as follows: How do people experience living with a person with MS? Two subquestions were as follows: (i) What are the key experiences of people who live with a person with MS? and (ii) What are the common themes that underpin these experiences?

2.4 | Identification of studies

Systematic searches were conducted in ProQuest, PubMed, CINAHL and PsychINFO databases of research papers published between 1 January 2003 and 1 January 2021 in English. The final search string used was ('multiple sclerosis') AND (experienc* OR perception* OR perspective* OR attitude* OR belief* OR value* OR view*) AND (qualitative OR "focus group*" OR interview* OR narrative*) AND (carer* OR caregiver* OR 'support person*' OR parent* OR child* OR brother* OR sister* OR sibling* OR friend* OR family OR families OR

partner OR spouse OR husband OR wife). Hand searches were undertaken of the references included in each paper.

2.5 | Selection of studies

Studies were included if they reported empirical qualitative data about individuals' subjective experiences of living with a person living with MS, were written in English and published in peer-reviewed journals. Mixed-method studies were included if qualitative results could be interpreted separately, and studies that included the experience of others (e.g., clinicians, paid carers, people living with MS) were included if the results related to individuals living with people living with MS could be interpreted separately. Reference lists of the included studies were checked. The grey literature was excluded.

2.6 | Study quality assessment

All included studies were appraised using the Critical Appraisal Skills Programme (CASP) qualitative checklist²⁰ by two researchers working independently (A. P., C. B.). Title and abstract screening, and full-text screening were performed by two reviewers (A. P., C. B.), and conflicts were resolved by a third reviewer (Jane Desborough).

2.7 | Charting the data

Interpretation and coding began at title and abstract screening and were refined as the data were reviewed. Final coding was performed using NVivo 12 qualitative data analysis software.²¹ Blinded audits of articles were undertaken during analysis to ensure that similar codes and concepts were being applied by two reviewers (A. P., C. B.), and differences were discussed with a third reviewer (Jane Desborough) until consensus was reached. This was followed by a meta-synthesis and generation of analytical themes that generated new interpretations of the data,^{19,22} framed by key elements of personhood (identity and the social world) and sociopolitical elements of caring.

2.8 | Patient and public contribution

Patient and public involvement underpins all our research and we have developed longstanding relationships with people in the MS community with whom we work closely, involving them in all aspects of our projects from inception and throughout analysis and preparation of publications. Our research team includes four members with MS and two members with lived experience of living or working with people with MS. They contributed to determining suitable search terms and ongoing discussion of emerging themes throughout the research. A third person (not a team member) who lives with a partner with MS provided feedback on the paper.

3 | RESULTS

The initial search yielded 330 articles, 49 of which were included in the review (Figure 1). The included articles originated from a range of countries (Table 1), and the quality of all studies was considered acceptable on the basis of the CASP tool (Table 2).

People living with a person with MS included women and men who identified as a partner or spouse of a person with MS, next of kin, support person, child of a parent with MS and parent of a child with MS. Experiences were expressed in relation to two distinct time periods—present day-to-day existence and the future. Uncertainty was evident in the experiences of most participants and permeated all aspects of life. The experiences described ranged from positive experiences of empowerment and personal growth to negative experiences of disempowerment—encompassing anger, frustration, guilt and helplessness. The ability of people living with a person with MS to accept, and adapt to, the diagnosis of MS of someone close to them, and adapt their lives and the lives of their family to live with their changed circumstances varied. Their position was not static and ebbed and flowed in line with the symptoms of the person with MS, often mirroring their journey.

Five themes were identified that described the experience of living with a person with MS (Table 3): One of these—*seeking information and support*—reflects the political economy of care. Two are concerned with the moral domain of care: *the labour of care* and *living with uncertainty*. The final two themes—*changing identities* and *adapting to life with a person with MS*—point to the negotiation and reconstitution of personhood for both the person with MS and the person they live with.

3.1 | Seeking information and support

Carers reported being excluded from a care ecosystem organized around the health care provider and the person with MS. Partners,²⁶ carers of persons transitioning to secondary progressive MS and³⁴ parents of children with MS, especially while in pursuit of a diagnosis,^{55,56,61} reported feeling ignored and undervalued by clinicians who did not treat them as equal partners in the health care relationship. Young carers of a parent with MS noted, in particular, that they were marginalized by clinicians whose focus was solely on the parent.^{27,28}

The initial diagnosis was described by partners and parents of people with MS as being a shared and emotionally challenging experience.^{23,55} This was compounded by lack of knowledge about MS and inaccurate or negative preconceptions about MS, including expectations of severe disability.^{24,25,61} Most studies identified pressing needs for clinicians to provide informational, practical and emotional support for carers,^{25,27,29,30,34,36–44} support persons,²³ partners^{26,31,35,43–51} and family members,^{24,25,33,40,50,53,54} including parents^{32,55,56,61} and children of people with MS.^{24,27,28,30,33,54,59,60}

In this setting of knowledge asymmetry, information gathering became a valued activity undertaken by partners or family members

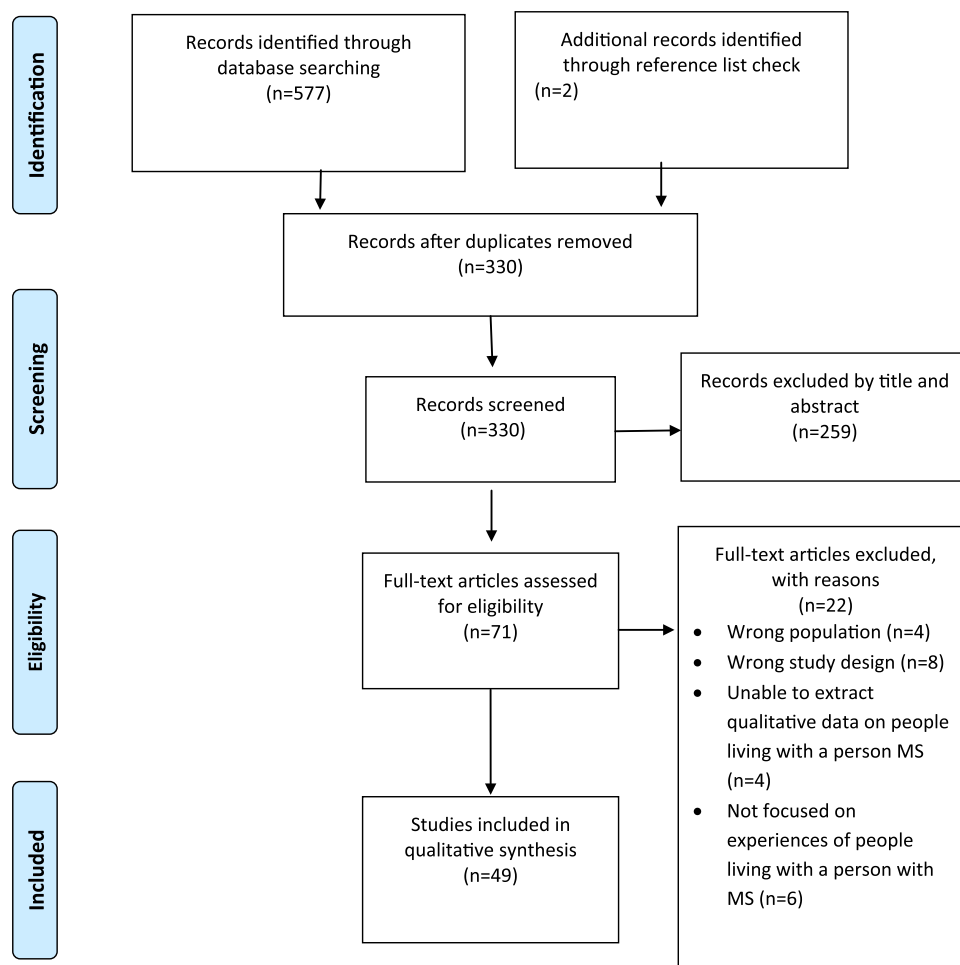


FIGURE 1 PRISMA flow diagram

of a person with MS.⁵⁰ In their search for knowledge, people living with a person with MS accessed information from multiple sources outside the health system, including the internet,^{25,33,34,40,47,50,55–58} books,^{29,33,47,50,55,58} peer support networks,^{29,40,50,55,57,58} forums,^{50,55,57} blogs,^{50,55,57} media,^{33,40,50,55} friends,^{34,47,50,55} family,^{50,55} relevant literature⁵² and MS associations.^{29,47,50,56,57}

3.2 | Caring as labour

Most studies described the challenging aspects of a caring role when living with a person with MS—as a partner,^{26,29,34–36,38–40,43–47,51,63} informal carer,^{27,31,35,37,42,46,51,58,65,69} parent,^{32,55} child^{27,30,54,59,60,64} or family member^{24,37,53,68} of a person with MS. Caring activities included, but were not limited to, providing emotional support, personal/intimate care, physical care, household tasks and advocacy.⁶² Care was represented as a positive activity by some, enabling personal growth by carers supporting a partner,^{35,43,47,58,66} parent^{59,60} or family member⁵³ with MS.

Many studies also noted that care was experienced as a form of moral labour, marked by the interdigitation of domestic and

health needs of persons with MS and the person living with them.^{23,45,47,50,51,59,68} Participants felt an obligation to care for the person with MS,^{40,43,44,48,62,63} including their young and older children.^{27,59,60,64} Participants in some studies described care as a duty,^{62,64} part of their commitment to marriage^{34,43} or a sacrifice.^{30,35–37,44,48,51,62,65–67} Some participants, including children of persons with MS,^{27,28,30,64} felt unacknowledged and that their role as a caregiver was not valued by health care practitioners,^{26,27,34,35} the community^{35,62,64} or the person with MS.^{30,65} Several studies reported gender disparities, with men believing that they were less suited to a caring role than women^{44,47,65}; some women agreed.^{47,65}

3.3 | Living with uncertainty

Uncertainty about MS diagnosis, treatment, prognosis and management underpinned the experiences and concerns of people living with a person with MS. The unpredictable trajectory of MS was presented as a constant source of worry for partners,^{43,44,46,47,51,58,68,70} carers,^{25,34–36,39,42,65} support persons,²³

TABLE 1 Summary of the included studies

Author (year)	Country	Population	n	♀	♂	Age	Aims	Findings	T1	T2	T3	T4	T5
Theme 1 (T1) Seeking information and support													
Theme 2 (T2) Caring as labour													
Theme 3 (T3) Changing identities													
Theme 4 (T4) Living with uncertainty													
Theme 5 (T5) Adapting to life with a person with MS													
Bjorgvinsdottir et al. (2014)	Iceland	Young carers of PwMS	11	6	5	5–18	To study the personal experience of being a young caregiver of a PwMS.	Young carers felt unsupported and isolated. Health professionals need to provide information, support and guidance for young carers.	X	X	X	X	X
Boeije et al. (2003)	The Netherlands	Spouses of PwMS	13	5	8	48–75	To examine how spouses experience caregiving when motivated by a sense of duty.	Health professionals need to recognize that women may be at greater risk of physical and psychological illness and need support.	X	X	X	X	X
Bogosian et al. (2011)	England	Adolescents of a parent with MS	15	10	5	13–18	To explore how adolescents with a parent with MS adjust to their parents' illness.	Support interventions may be helpful for vulnerable adolescents that consider family and individual factors.	X	X	X	X	X
Bogosian et al. (2009)	England	Partners of PwMS in early stages	15	10	5	32–59	To explore and describe the experiences of partners of PwMS in early stages of MS.	There is a need for health professionals to provide support that focusses on the needs of partners.	X	X	X	X	X
Boland et al. (2012)	NZ	Partner of PwMS PwMS	7	3	4	43–74	To explore how PwMS and their partners cope as a couple.	Clinicians need to be sensitive to the individual coping strategies of both members of a couple.	X	X	X	X	X
Borreani et al. (2014)	Italy	Partner of PwMS PwMs Clinicians	30	16	14	24–91	To identify unmet needs of PwMS living at home with caregivers.	Unmet needs transcended medical issues and embraced psychosocial themes. Lack of support was a critical issue.	X	X	X	X	X
Boss and Finlayson (2006)	US	Carer of PwMS PwMS uses mobility aid	4	2	2	32–69	To explore reactions of family members of a PwMS using power mobility.	Family members had difficulties finding credible sources for information and advice concerning power mobility.	X	X	X	X	X
Bostrom and Nilsagard (2016)	Sweden	Child of PwMS Partner of PwMS PwMS	9	5	4	12–24	To explore issues that are important to acknowledge for a child to cope with a parent with MS.	MS affects the whole family. Health professionals need to support the whole family and empower parents to help children cope.	X	X	X	X	X
Carling et al. (2018)	Sweden	Next of kin of PwMS	20	5	15	26–76	To describe life experiences of next of kin living with a PwMS who falls.	Next of kin are affected by the falls of their cohabiting person. They need practical and emotional support from the health care system.	X	X	X	X	X

(Continues)

TABLE 1 (Continued)

Author (year)	Country	Population	n	♀	♂	Age	Aims	Findings	T1	T2	T3	T4	T5
Carroll et al. (2016)	UK	Adolescents with MS Parents	15 13	8 11	7 2	9–18 32–52	To explore experiences of MS fatigue in the family and how this is managed.	Fatigue is uncontrollable, uncertain and unpredictable and a lack of information exists for PwMS and their carers to manage it.	X	X	X	X	X
Cheung and Hocking (2004a)	Australia	Spousal carers of PwMS	10	4	6	40–60	To explore lived experiences of spousal carers of PwMS.	Carers' values, concerns and connections with their partner and others shape their way of coping. Health professionals need to provide support and care tailored to their needs.	X	X	X	X	X
Cheung and Hocking (2004b)	Australia	Spousal carers of PwMS	10	4	6	40–60	To explicate the meaning of caring from carers of PwMS.	Caring is a complex emotional relationship of responsibility for carers. They worried about their partners, the future, their own health, institutional care and lack of government support.	X	X	X	X	X
Courts et al. (2005)	US	Spousal carers of PwMS	12	4	8	31–67	To investigate the experiences of spouses of PwMS.	Spouses need information about MS and psycho-social support. Nurses are well placed to provide information, encourage joining of support groups and offer guidance.	X	X	X	X	X
Davies et al. (2015)	Wales	Carers of PwSPMS PwSPMS	14 20	6 15	8 5	31–80 31–80	To explore experiences of PwMS and their partners in the transition to SPMS.	The process of diagnosing the transition to SPMS was often not transparent and people wanted credible information from health professionals about the transition.	X	X	X	X	X
Dibley et al. (2017)	England	Carers of PwMS PwMS	6 41	4 31	2 10	28–76 28–76	To understand the impact of bowel dysfunction on PwMS and carers.	Bowel dysfunction impacts the lives of people with MS and their carers. Bowel issues to be discussed more openly, with clinicians instigating a discussion early after MS diagnosis and repeating enquiries regularly.	X	X			
du Plooy and Pretorius (2014)	South Africa	Carers of PwMS	8	5	3	28–70	To explore the lived experiences of caregivers of PwMS.	Carer support should be tailored to suit the unique situation of each caregiver and the varied presentation of MS.	X	X	X	X	X
Ebrahimi et al. (2017)	Iran	Carers of PwMS	18	14	4	27–54	To explore the coping strategies of family caregivers of PwMS.	Spiritual connection was key to coping for Iranian family caregivers. Health care providers need to recognize this as they communicate, inform and offer support.	X	X			X
Edmonds et al. (2007)	England	Carers of PwMS PwMS	32 6				To explore the perceptions of PwMS and their carers about their illness and care.	There is a need to better meet patients and carers needs for information, co-ordination of care and to reduce the feeling of struggling to receive services.	X				

TABLE 1 (Continued)

Author (year)	Country	Population	n	♀	♂	Age	Aims	Findings	T1	T2	T3	T4	T5
Esmail et al. (2010)	Canada	Men with MS Female partners	4 4	4 0	0 4	18–60	To understand the experiences of couples' sexual relationship when a male partner has MS.	Clinicians should facilitate open communication, recognize each partner's intimacy needs and assist both partners.	X	X			
Esmail et al. (2007)	Canada	Women with MS Male partners	6 6	6 0	0 6	32–58	To understand the experiences of couples' sexual relationship when a female partner has MS.	Health professionals need to recognize that intimacy needs to be addressed with couples.	X	X	X	X	X
Fakolade et al. (2018)	Canada	Carers of PwMS PwMS	12 22	6 16	6 6	38–79 37–71	To explore shared experiences of physical activity by caregiver/care-recipient dyads.	Clinicians need to target the health and well-being of both the caregiver and the PwMS as an interdependent unit.	X	X	X	X	X
Gafari et al. (2017)	Iran	Carers of PwMS	23				To explore the perceptions of caregivers about caring for a PwMS.	Clinicians need to recognize carers and provide support and information.	X	X	X	X	X
Hebert et al. (2019)	US	Parents of child with MS	42	40	2		To explore experiences of parents receiving the diagnosis of MS for their child.	Diagnosis of paediatric MS is a difficult time for families where additional support and information is needed.	X				X
Hinton and Kirk (2017)	UK	Parents of child with MS	31	20	11		To explore the experiences of parents living with childhood MS.	Health care professionals need to be sensitive to the role that hope plays in supporting parental coping with childhood MS.	X				
Hinton and Kirk (2015)	UK	Children with MS Parents	21 31	15 20	6 11	8–17	To explore diagnosis experiences of parents of children with MS.	Diagnosis of paediatric MS is a lengthy and uncertain process. Clinicians can aid early diagnosis by listening carefully to parents.	X	X	X	X	X
Hughes et al. (2013)	UK	Carers of PwMS	48	29	19	17–75	To examine the role of the carer among family members and friends of PwMS.	Self-identification with the role and label of carer is nuanced, shifting and variable. Health and social care professionals need to understand caregiving identity to provide suitable support.	X	X	X	X	X
Jonzon and Goodwin (2012)	Canada	Daughters of mothers with MS	4	4	0	19–26	To understand the play experiences of daughters of mothers with MS.	Children of a PwMS experienced guilt and worry as a result of caregiving that matured them beyond their years.	X	X	X	X	X
Liedstrom et al. (2010)	Sweden	Next of kin to PwMS	44	24	20	19–70	To examine the psychological well-being of next of kin of PwMS.	Nurses are well placed to start family support groups; nursing interventions that focus on resources for the family of a PwMS are needed.	X	X	X	X	X
Masoudi et al. (2017)	Iran	Carers of PwMS	14	7	7	20–45	To investigate the experiences of family caregivers of PwMS about stigmatization.	Health care professionals need to provide support for family caregivers of a PwMS to deal with stigma, including teaching social engagement strategies.	X				

(Continues)

TABLE 1 (Continued)

Author (year)	Country	Population	n	♀	♂	Age	Aims	Findings	T1	T2	T3	T4	T5
Masoudi et al. (2014)	Iran	Carers of PwMS	14	7	7	20–45	To explore the challenges of family caregivers of PwMS.	Emotional and spiritual support for family caregivers is needed.	X	X	X	X	X
Masterson-Algar and Williams (2020)	North Wales	Young adults with a parent with MS	14	9	5	16–25	To examine the impact that having a parent with a neurological condition can have on young adults' experiences of growing up.	Young adults reported feelings of abandonment and lack of support from school, peers and services. More initiatives need to be put in place to identify and support these young people.	X	X	X	X	X
Mauseth and Hjalmskult (2016)	Norway	Children of a PwMS	15	8	7	12–18	To examine adolescents' experiences of having a parent with MS.	Adolescents of a PwMS need knowledge about MS, good family functioning and support from health professionals; long-term intervention programmes offering information and guidance are needed.	X	X	X	X	X
Mazanderani et al. (2019)	UK	Family/carers of PwMS	60	34	26		To explore the health information work of family members of a PwMS.	When developing information services, it is important that partners and other family members of a PwMS are taken into consideration; clinicians need to find out who the key 'information worker' is within a family.	X	X	X	X	X
McKeown et al. (2004)	Ireland (Northern and Republic)	Carers of PwMS	17	11	6	18–65	To gain an understanding of the experiences of caregivers of PwMS.	Health professionals need to be aware that a caregiver's attitude and acceptance of support with caregiving may change over time; tailored interventions to individual needs are required.	X	X	X	X	X
Moberg et al. (2017)	Denmark	Young adults with a parent with MS	14	12	2	18–25	To explore young adults' experiences of growing up with a parent with MS.	Health care professionals can support the family coping with chronic parental illness by promoting openness and knowledge about the illness. Some of the children need psychological help on a long-term basis.	X	X	X	X	X
Mutch (2010)	England	Spouses of PwMS	8	4	4	50–74	To understand the experiences of the partner living with and caring for a spouse with MS.	Partners felt obligated to care and a sense of loss as they prioritized the partner. Health professionals need to provide informational and emotional support.	X	X	X	X	X
Neate et al. (2020)	Australia New Zealand UK Switzerland	Partners of PwMS	21	6	15	20–79	To explore the views of partners of PwMS about the future and how engagement with lifestyle modification may have impacted these views.	Lifestyle modification enabled some partners to develop a sense of empowerment and control, and a subsequent confidence and positivity about their future.	X	X	X	X	X

TABLE 1 (Continued)

Author (year)	Country	Population	n	♀	♂	Age	Aims	Findings	T1	T2	T3	T4	T5
Neate et al. (2019b)	Australia New Zealand UK Switzerland	Partners of PwMS	21	6	15	20–79	To explore the experiences of partners of PwMS who have adopted lifestyle modification and the impact on the couple's intimate relationship.	Positive relationship benefits were experienced around improved communication and having a greater sense of closeness and feeling more connected.	X	X			X
Neate et al. (2019a)	Australia New Zealand UK Switzerland	Partners of PwMS	21	6	15	28–79	To explore changes made by partners of PwMS to improve well-being.	A broad range of support from family, friends and health care professionals can assist in making and maintaining lifestyle changes.			X		X
Neate et al. (2018)	Australia New Zealand UK Switzerland	Partners of PwMS	21	6	15	28–79	To explore the experiences of partners of PwMS who have adopted lifestyle modification.	Positive psychological changes were experienced by some partners of PwMS embracing lifestyle modifications including acceptance of MS and adaptation to it.					X
Nilsagard and Bostrom (2015)	Sweden	Children of PwMS Partner of PwMS PwMS	9 5 9	5 1 7	4 4 2		To explore how health care services can support children of a parent with MS.	Parents with MS should be supported and advised to discuss the situation frequently with their children; forums for discussion should be offered.	X				X
Rollero (2016)	Italy	Male carers of PwMS	24	0	24	37–68	To explore the experience of male carers of a partner with MS.	Social expectation and gender norms impact male caregivers. Health professionals in particular need to provide tailored support for male spousal caregivers.	X	X	X	X	X
Shapiro et al. (2013)	US	Carers mistreated PwMS PwMS	7 8	4 5	3 3	34–85	To explore views on, and disclosure of, mistreatment of PwMS.	There is a need for educational and support groups for caregivers who disclose mistreatment of PwMS.		X	X	X	X
Sillence et al. (2016)	UK	Carers of PwMS	20	13	7	39–73	To explore what kinds of online support carers of a PwMS prefer.	Carers of PwMS found online support engaging and useful; accounts were most compelling where there was a strong sense of shared identity.	X				
Strickland et al. (2015)	Scotland	Support persons of PwMS	9	5	4	25–80	To explore the experience of the MS diagnosis for the support person.	The uncertainty following diagnosis about the nature and progression of MS left the support person transitioning to that of 'anticipatory carer'.	X	X	X	X	X
Tehranehshat et al. (2020)	Iran	Family caregivers of PwMS	18	13	5	27–60	To identify family caregivers' experiences at the first hospitalization of their patients.	The psychological and social problems of family caregivers can adversely affect their coping mechanism.	X			X	X

(Continues)

TABLE 1 (Continued)

Author (year)	Country	Population	n	♀	♂	Age	Aims	Findings	T1	T2	T3	T4	T5
Topcu et al. (2020)	England UK Cyprus	Carers of PwMS	12	7	5	30–73	To explore the experiences of carers of PwMS and their quality of life through the use of images and narratives.	The nature of carers' quality of life is complex and whilst mostly negative, some positive aspects ameliorate these.	X	X	X	X	X
Turpin et al. (2008)	Australia	Children of PwMS	8	4	4	7–14	To explore the experiences of children who have a parent with MS.	Parental MS affects the roles and responsibilities of the whole family. Children worry about the well-being of their parent; social and practical support for the parent could reduce children's anxiety.	X	X	X	X	X
Wawrziczny et al. (2019)	France	Partner of PwMS PwMS	6 6	1 5	5 1	29–50	To explore the experiences of couples where one has MS.	Health professionals need to provide early interventions and support for individuals to learn acceptance and for couples to maintain emotional communication.	X	X	X	X	X

Abbreviations: PwMS, person with multiple sclerosis; PwSPMS, person with secondary progressive multiple sclerosis.

children^{24,28,30,33,54,58–60,64} and parents of people with MS,^{25,32,55} and their next of kin.³⁷ This existential uncertainty was psychologically distressing for partners who described not knowing how to help the person with MS⁶⁶ and for carers worried about being unable to care for them if they themselves were unwell.^{27,36,42,46} Faced with an uncertain future, participants in many studies reported experiencing anxiety and depression,^{31,36,41,58,63,65,66} including children.^{27,28,30,54,60} The MS diagnosis was overwhelming and worrying for children, and often continued into adulthood.^{27,60} Some children worried about burdening their parents, and described concealing their feelings and making efforts to reassure them that they were coping.^{59,60}

3.4 | Changing identities

Four studies described the struggle of people living with a person with MS to maintain their sense of self in the face of changing roles, as the person with MS transitioned from healthy partner or family member to one needing support.^{23,26,35,62} While people carried out a wide range of caring activities, not everyone identified as a 'carer', some preferring instead to be recognized according to their relationship (e.g., partner, sister, mother),⁶² especially in the early stages when transitioning to becoming a future or 'anticipatory' carer.²³ The role of 'carer' could shift and vary over time.⁶² Some spouses and partners reported a shift in their sense of self as being individual—characterized by independence, strength and freedom—to being intertwined, subsumed by caring and support of the person with MS. Many experienced a sense of loss^{35,44}; they felt that MS had changed their partner, the dynamics of their relationship and themselves.^{43,53,63,65} Those who had to stop or reduce their work sometimes experienced a loss of self and status.^{35,37,58,63} Some children acting as caregiver to a parent with MS described a reversal of the parent–child role,^{59,64} with others reporting taking on parental obligation for younger siblings as well as parenting themselves.^{27,54,60} Many experienced a loss of connectedness with friends, family and work colleagues as their social lives contracted.^{24,26,34,36,37,39,41,42,44,48,53,58,63,68} Participants—particularly children of people with MS^{24,27,54,60}—described a sense of becoming invisible as family, friends or health care providers never asked about them, only about the person with MS.^{24,37}

Few studies focused on gendered perspectives or gender roles of people living with a person with MS. Four studies about the experiences of spousal caregivers considered the differing perspectives of women and men in the context of their sexual relationship and changing roles,^{48,49} and ability to care more broadly.^{44,63} One study found that women give care and take on more responsibilities in response to societal expectations, whereas men believed that they were going beyond such expectations when they give care.⁶³ Only one study specifically examined the experiences of adult male partners caring for a person with MS in relation to gender norms and the difficulties that they faced showing vulnerability and seeking support.⁴⁴

TABLE 2 CASP (Critical Appraisal Skills Programme) assessment

Author	Year	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10a	Q10b	Q10c
Question 1: Are the results valid?													
Question 2: Is a qualitative methodology appropriate?													
Question 3: Was the research design appropriate to address the aims of the research?													
Question 4: Was the recruitment strategy appropriate to the aims of the research?													
Question 5: Was the data collected in a way that addressed the research issue?													
Question 6: Has the relationship between researcher and participants been adequately considered?													
Question 7: Have ethical issues been taken into consideration?													
Question 8: Was the data analysis sufficiently rigorous?													
Question 9: Is there a clear statement of findings?													
Question 10: How valuable is the research?													
a. Discussion of the contribution the study makes to existing knowledge													
b. Identification of new areas where research is necessary													
c. Discussion of how the findings can be transferred to other populations													
Bjorgvinsdottir et al.	2014	Y	Y	y	y	y	y	y	y	Y	Y	N	Y
Boeije et al.	2003	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y
Bogosian et al.	2011	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Bogosian et al.	2009	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Boland et al.	2012	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Borreani et al.	2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Boss and Finlayson	2006	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	N
Bostrom and Nilsagard	2016	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	Y
Carling et al.	2018	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Carroll et al.	2016	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	N
Cheung and Hocking	2004a	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Cheung and Hocking	2004b	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Courts et al.	2005	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Davies et al.	2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Dibley et al.	2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
du Plooy and Pretorius	2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Ebrahimi et al.	2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Edmonds et al.	2007	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	Y
Esmail et al.	2007	Y	Y	Y	CT	Y	CT	CT	CT	Y	Y	Y	Y
Esmail et al.	2010	Y	Y	Y	CT	Y	CT	CT	CT	Y	Y	Y	Y
Fakolade et al.	2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Gafari et al.	2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Herbert et al.	2019	Y	Y	Y	Y	Y	N	Y	CT	Y	Y	Y	N
Hinton and Kirk	2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Hinton and Kirk	2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	y	N	N
Hughes et al.	2013	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	y

(Continues)

TABLE 2 (Continued)

Author	Year	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10a	Q10b	Q10c
Jonzon and Goodwin	2012	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y
Liedstrom et al.	2010	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Masoudi et al.	2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Masoudi et al.	2017	Y	Y	Y	Y	Y	N	Y	Y	Y	y	N	Y
Masterson-Algar and Williams	2020	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Mauser and Hjalmlult	2016	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Mazanderani et al.	2019	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	N
McKeown et al.	2004	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Moberg et al.	2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Mutch	2010	Y	Y	Y	Y	Y	N	Y	Y	Y	N	N	Y
Neate et al.	2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Neate et al.	2019a	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Neate et al.	2019b	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Neate et al.	2020	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Nilsagard and Bostrom	2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	CT
Rollero	2016	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Shapiro et al.	2013	Y	Y	Y	CT	Y	CT	CT	Y	Y	Y	Y	N
Sillence et al.	2016	Y	Y	Y	Y	Y	CT	Y	CT	Y	Y	Y	N
Strickland et al.	2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Tehranehsat et al.	2020	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Turpin et al.	2008	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Topcu et al.	2020	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Wawrziczny et al.	2019	Y	Y	Y	CT	Y	CT	Y	Y	Y	Y	Y	Y

Abbreviations: CT, cannot tell; N, no; Y, yes.

3.5 | Adapting to life with a person with MS

People who live with people with MS face a need to develop a long-term management approach to the challenges to identity, living with uncertainty and the moral demands of care. People used various adaptation strategies. Acceptance was viewed as the first step,^{23,26,37,40,45,48,66} including for children.^{24,30} Spiritual beliefs helped some,^{25,39,40} whereas others focused on hope for a cure or slow disease progression.^{26,40,45,66} Many made a conscious effort to live in the present rather than dwelling on the future,^{34,35,37,39,45,53,57} and many resolved to not focus solely on MS, but concentrate on living as normal a life as possible.^{23,24,26,31,37,44,53,63} In contrast, some partners or carers chose to distance themselves from the person with MS.^{35,46,51,63} In one study, the emotional cost of caregiving led to resentment and intentional mistreatment.⁶⁵ The most valued coping

strategy was maintaining personal well-being and taking time out for themselves,^{24,36,37,43,48,58,62,65–67} and speaking to someone about their situation to relieve emotional tension.^{23,26,28,47,51,58,65} Social support from friends and family members was a key enabler for children of a person with MS.^{27,28,30,54,59,64}

Some participants found that even though they might have been placed in situations outside their comfort zone, they learned to be adaptable, face challenges and develop new skills,^{35,40,44,47,48,60,66,70,71} connect and communicate better with their partner⁷⁰ and reassess their lives to determine what they most valued.⁶⁶ Others learned to value and embrace their role as a carer, feeling a sense of pride and accomplishment.⁶² Young adults also experienced personal growth through acting as a caregiver of a parent with MS, which built confidence, independence and resilience,^{28,30,59,60,64} often leading them to health-related education and professions later in life.⁶⁰

TABLE 3 Thematic framework

Theme	Related experiences
Seeking information and support	Initial diagnosis of person with MS was a shared and emotionally challenging experience, ²³ further impacted by their own lack of knowledge and negative perspective about MS ^{24,25}
(Adults living with a person with MS)	Dissatisfaction with health care providers,^{23–32} not knowing where to turn for information,^{25,27,33} role of caregiver not valued^{26,27,34,35} Need for health care providers to provide information and support for carers,^{25,27,29,30,34,36–44} support persons,²³ partners and^{26,31,35,43–52} family members^{24,25,33,40,50,53,54} Participants needed to take on the task of sourcing information elsewhere and accessed the internet,^{25,33,34,40,47,50,55–58} books,^{29,33,47,50,55,58} peer group support networks,^{29,40,50,55,57,58} forums,^{50,55,57} blogs,^{50,55,57} media,^{33,40,50,55} friends,^{34,47,50,55} family,^{50,55} relevant literature⁵² and MS associations^{29,47,50,56,57}; information gathering was a valued role often undertaken by the partner/family member.⁵⁰
Seeking information and support	Dissatisfaction with health care providers, ^{24,27,28,30,32} not knowing where to turn for information, ^{27,33} role of caregiver not valued ^{26,27}
(Children of a parent with MS)	Need for health care providers to provide both information and support for children of parents with MS^{24,27,28,30,33,54,59,60} Received little information from health care providers^{24,27,28,30}; believed health care providers did not understand how the diagnosis affected them⁶⁰ No opportunity to discuss the illness with health care providers or within a support group led to confusion and fear²⁷ Valued having a clinician talk to them (children) about MS, receiving age-appropriate written materials and being referred to family group information sessions³³; accompanying a parent to a treatment session was helpful^{30,33} Desiring information from parents—believed parents uninformed,^{24,27,30} parents did not understand how the diagnosis that affected their child and⁶⁰ children better able to adjust when parents were open and informative about MS^{33,60} Lack of support at school,²⁸ which made it difficult to manage school workloads, increased potential dropping out, teachers did not understand about living with a chronically ill parent and^{27,59} some adolescents received support from their school nurse³⁰
Seeking information and support	Initial diagnosis was distressing, ⁵⁵ further impacted by their own lack of knowledge and negative perspective about MS and implications for future potential disability of their child ⁶¹
(Parents of a child with MS)	Parents could not rely on health care providers and sourced information elsewhere from the internet,^{55,56} books,⁵⁵ peer group support networks,⁵⁵ forums,⁵⁵ blogs,⁵⁵ media,⁵⁵ friends and family and⁵⁵ MS associations⁵⁶ Difficulty getting diagnosis as paediatric-onset MS not well recognized, not being heard; opinion of parents not valued, lack of information and support tailored to needs of children,^{32,55,56,61} hearing the diagnosis at the same time as their child/no warning was disempowering⁵⁶ Positive experiences included being consulted about sharing diagnosis with the child, being supported/listened to, being provided with age-appropriate resources and connecting parents to support groups⁶¹
Caring as labour	Caring incorporates emotional support, personal care, physical care, household tasks and advocacy ⁶²
(Adults living with a person with MS)	Reasons for taking on the role included obligation,^{40,43,44,48,62,63} duty,^{62,64} as part of commitment to marriage,^{34,43} sacrifice,^{30,35–37,44,48,51,62,65–67} intertwined nature of the relationship between the person with MS and the person living with them^{23,45,47,50,51,68} Specific symptoms to manage (balance and falling,³⁷ bladder and bowel dysfunction,^{38,65} mood swings,^{47,66,69} sexual dysfunction,^{48,49} fatigue^{26,39,63}) Challenging aspects reported by partner,^{26,29,34–36,38–40,43–47,51,58,63} carer,^{27,31,35,37,42,46,51,58,65,69} parent of a child with MS and^{32,55} family member^{24,37,53,68} Recognition of positive experiences supporting a partner,^{35,43,47,52,66} family member⁵³ Men believed that they were less suited to the caring role than women^{44,47,65}; some women agreed^{47,65} Challenges identified included time-consuming and hard work,^{26,31,34,35,37,39,43,44,46,51,62,63,65,68} it is a 'full time job',^{39,44,62,63} extra household tasks increasingly taken on,^{34,35} those who worked found it progressively more demanding,⁶³ constant need to plan ahead for any activity was taxing,^{26,35,37,44,51} responsibility of decision-making was a burden,⁶⁸ acting on their behalf was a burden,⁵⁰ having to provide intimate care was difficult and confronting³⁸

(Continues)

TABLE 3 (Continued)

Theme	Related experiences
	Some participants felt unacknowledged and not valued by health care providers, ^{26,34,35} the community and ^{35,62} the PwMS ⁶⁵
	Changes in the nature of the relationship were challenging and occurred in the early stages of MS, ^{23,26} sexual relationship, ^{48,49} as the condition progressed and physical/mental capacities were affected ^{35,37,38,43,44,46,47,53,62,63}
Caring as labour	Reasons for taking on the role included obligation ^{27,59,60,64} and recognition of the intertwined nature of their relationship with their parent with MS ⁵⁹
(Children of a parent with MS)	Specific symptoms to manage included bladder and bowel dysfunction, ²⁴ mood swings and ²⁴ fatigue ^{24,30,64} Challenging aspects of caring reported ^{27,30,54,59,60,64} Recognition of positive aspects of supporting a parent ^{59,60} Challenges identified included time-consuming and hard work, ^{24,27,34,59} children tired from extra household responsibilities, ^{27,54,59,64} constant need to plan ahead for any activity was taxing and ²⁴ having to provide intimate care was difficult and confronting ^{27,54} Some children felt unacknowledged and not valued by health care providers, or the community, or their parent with MS ^{27,28,30,64}
Changing identities	Hard to maintain sense of self in the face of changing roles, expectations and identity as the person with MS transitions from healthy partner or family member to one needing support ^{23,26,35,62}
(Adults living with a person with MS)	Not all identify as a 'carer' believing the label limiting, ^{23,62} especially in the early stages, when transitioning to becoming a future or 'anticipatory' carer ²³ Role of 'carer' shifting and variable over time, adopted to differing degrees ⁶² MS changed their partner, the dynamics of their relationship and themselves ^{43,53,63,65} Loss of a partner, a friend, a lover or a coparent, who was replaced by a person who needed ongoing support ^{35,44} Loss of self and status as a person with paid employment and one valued by society, ^{35,37,58,63} becoming invisible as family, friends or health care providers ask only about the PwMS ³⁷ Loss of connectedness with friends, family and work colleagues as social lives became significantly reduced, ^{24,26,34,36,37,39,41,42,44,48,53,58,63,68} lack of spontaneity due to need for constant planning, ^{26,35,37,43,44,58} foregoing shared activities with partner, ^{24,26,34,37,48,58,63,66,67} people feel uncomfortable when a person is in a wheelchair, ³⁵ access to homes and public places difficult with a wheelchair, ^{37,42,44,58,68} some independence restored when the PwMS obtained a mobility aid ⁶⁸
Changing identities	Role of parent/child reversed, with the child acting as a parent ^{59,64} Parenting themselves and younger siblings ^{27,54,60}
(Children of a parent with MS)	Did not identify with others the same age as more mature/different priorities ^{59,64} Becoming invisible as family, friends or health care, providers ask only about the person with MS ^{24,27,54,60} Reduced social life, lack of spontaneity and less time with friends ²⁴ Shaped/changed every aspect of their lives and identity ²⁸
Living with uncertainty	Four key uncertainty time points were identified: during diagnosis, in daily life, during social or clinical interactions and when thinking about the future ⁵⁵
(Adults living with a person with MS)	Unpredictable trajectory of MS a constant source of worry for partners, ^{43,44,46,47,51,58,68,70} carers, ^{25,34-36,39,42,58,65} support persons, ²³ parents of person with MS and ^{32,55} next of kin ³⁷ Uncertainty was psychologically distressing for partners who described apprehension, uncertainty and guilt around not knowing how to help the PwMS ⁶⁶ Carers worried about getting sick and being unable to care for the PwMS, ^{36,42,46} with many reporting anxiety and depression ^{31,36,41,63,65,66}
Living with uncertainty	Uncertain future caused constant worry ^{24,28,30,33,54,59,60,64} Children experienced anxiety and depression ^{27,30,54,60} MS diagnosis overwhelming and worry inducing, often continuing into adulthood ^{27,28,60}

TABLE 3 (Continued)

Theme	Related experiences
(Children of a parent with MS)	Some children concealed feelings, worried about burdening parents,^{28,59,60} some did not talk about it as it was not openly discussed within the family²⁷ Adolescents of a parent with MS reported being constantly worried about how the MS might progress,^{24,28,30} whether their parent was having a 'bad day',³⁰ whether the parent with MS had hurt themselves/needed assistance^{24,54,60} Some adolescents recognized they had become overprotective; worried continually whenever they were away,⁶⁴ felt they could not spend time with friends,^{54,59} were delaying leaving home,⁶⁴ feeling guilty if they left to pursue their education^{28,30}
Adapting to life with a person with MS	Acceptance,^{23,26,37,40,45,48,66} including children of a parent with MS^{24,30} and normalization as MS was gradually accepted into their family life, creating a new normality.^{24,59}
(Adults living with a person with MS)	Strong spiritual beliefs,^{25,39,40} hope for a cure or for slow disease progression,^{26,40,45,66} including for a parent,³⁰ comfort that MS was not a condition they feared might be worse for partner,⁴⁵ parent⁵⁹ or child.⁶¹ Establish positive relationships with like-minded people who are supportive⁵² Positive, supportive and nurturing relationships with health care providers for both the person with MS and partner highly valued, abandon negative influences such as health care providers who are unhelpful/unsupportive⁵² Not focus solely on MS, but concentrate on living as normal a life as possible,^{23,24,44,59} putting practical strategies in place for managing everyday life as needed, acquiring equipment to facilitate routine tasks and adapting living spaces to enable independence^{23,24,26,31,37,44,53,63}; some parents of children with MS chose to withdraw from support groups that acted as a constant reminder of MS⁵⁵ Some partners/carers chose to distance themselves from the person with MS, and^{35,46,51,63} for others the emotional cost of caregiving was overwhelming and they railed at the unfairness of life and their helplessness; for some, this anger led to resentment of the person with MS and intentional mistreatment⁶⁵ It was important for participants to maintain their health and well-being and to take time out for themselves, have a break from their stressful environment and socialize with friends^{24,36,37,43,48,52,62,65-67}; being able to speak to someone honestly about their situation helped to release emotional tension.^{23,26,47,51,65} Support outside of immediate family reduced after the initial diagnosis of the person with MS, leaving participants feeling isolated^{26,35,36,40-42,44} Support and encouragement provided by families enabled couples to adjust to change⁵² Positive experiences of personal growth and empowerment were reported by some participants who found that even though they might have been placed in situations outside their comfort zone, they learned how to be adaptable, face challenges and develop new skills,^{35,40,44,47,48,60,66,70,71} connect and communicate better with their partner⁷⁰ and reassess their lives to determine what they most valued⁶⁶ Some reassessed their lives and determined what they valued most, often appreciating and finding greater meaning in life, becoming less concerned about material things and prioritizing family over work^{52,66} Working together as a couple to achieve goals including better communication⁷⁰ Some valued and embraced their role as a carer, feeling a sense of pride and accomplishment, or seeing themselves as an expert, or in one case, taking on the role of campaigning for people with MS⁶²
Adapting to life with a person with MS	Some children of people with MS were ashamed or embarrassed about their parents' condition and did not want to discuss it with their friends or let other people know the degree to which they cared for them^{24,27,28,30,41,54,60}
(Children of a parent with MS)	Adolescents reported that they found respite by changing focus and listening to music, playing computer games, spending time with friends^{30,54} Social support from friends and family members was also a key enabler for children; it helped them to better adjust to a parent's MS by providing not only practical help in everyday tasks but also emotional support^{27,28,30,54,59,64} Some adolescents received support from their school nurse or doctor³⁰ Some young caregivers developed personal stability and inner strength by following the rules set down for their friends with normal family lives, which enabled them to create order, discipline and control in their own lives²⁷ Later in life, some young caregivers believed that it was support from their life partners that enabled them to move on and deal with their situation²⁷

(Continues)

TABLE 3 (Continued)

Theme	Related experiences
	Some learned how to be adaptable, face challenges and develop new skills ^{28,35,40,44,47,48,52,60,66}
	Young adults were also able to experience personal growth by acting as a caregiver, which built confidence, independence and resilience ^{28,30,59,60,64} ; many young adult carers choose to pursue health-related education stemming from their empathy for people with chronic illness and having to be responsible and organized from an early age ⁶⁰

Abbreviation: MS, multiple sclerosis; PwMS, person with multiple sclerosis.

4 | DISCUSSION

People with chronic illness are embedded in relational social networks of partners, family and friends, which are fundamental in the support of the personhood of people with MS; they are 'co-constituents of the patient's identity', assisting them to make sense of their world and self in times of disruption.⁷²

The five themes described in this review shed light on the intertwined experiences of people living with a person with MS as a partner, spouse, child, parent, family member or next of kin and the person with MS. Irrespective of their relationship with the person with MS and the severity of the condition, their experiences have commonalities. The two themes *living with uncertainty* and *caring as labour* were present across most studies. These two themes were integral to *changing identities* and drivers of *seeking information and support* and *adapting to life with a person with MS*.

The theme *seeking information and support* highlights the role taken on by people living with a person with MS in advocating and addressing asymmetries of knowledge. There is a particular urgency with MS, where early diagnosis and treatment is key to better outcomes,⁷³ and many people take on the role of advocacy early when the person with MS may be overwhelmed or too physically unwell to undertake this role themselves.¹² This underpins the critical need for information and practical and emotional support highlighted across the studies, as decisions about treatment options affect both the person with MS and those close to them. These 'decision partners' play a vital role in shared decision-making about treatment.⁷⁴ The literature included in our review indicates that people living with a person with MS, including families, are often treated as minor players by health care practitioners, resonating with previous research about chronic illness management.^{75,76}

The impact of chronic disease on family members is profound and spreads across all aspects of life including for both children⁷⁷ and parents. Young carers are both the most vulnerable and the most likely to be ignored within the health system. As demonstrated in the themes *caring as labour* and *changing identities*, caring can greatly influence the life course of young people both physically and psychologically, affecting their education, economic opportunities, friendships and social support networks.⁷⁸ Health care practitioners need to be aware of situations where a young person may provide most of the care to a parent, as this is an emotional burden and can severely affect them.⁷⁹ They may need ongoing support, especially to

manage priorities, including school workloads.^{79,80} An Australian study about services for younger carers recommended that support for families should be a policy priority so that young people do not have to take on roles that are disruptive to their own development, functioning and education.⁸¹

Purcal and colleagues⁷⁸ propose an analytical framework that aims to assist young carers to seek support and relieve tension, while at the same time working to mitigate their caring responsibilities, with the ultimate goal of preventing their entrenchment in a caring role. The enactment of this framework seeks to facilitate *adapting to life with a person with MS* and it removes the assumption that this adaptation necessarily incorporates a caring role. One related resource designed to support young carers is Talk-Link, an Australian-based service that offers telephone counselling and access to peers for different age groups over an 8-week period.^{78,82} Schools are also well placed to provide support for young carers and offer programmes to develop understanding among teachers and peers.⁷⁹ The experiences described by those who live with, care for and support a person with MS closely mirror those described by people with MS.¹⁵ Our results suggest that the negotiation and support of the personhood is a mutual process between the person living with them and the person themselves. The lives of the caregiver and the care recipient can mirror one another, with both losing autonomy, the caregiver through the acceptance of responsibility and the care recipient through needing care.⁸³ In effect, the lives of carer or family member, and the person with MS are intertwined, forming what has been described as a 'double helix', with their needs being 'largely inseparable'.⁸⁴ The contexts in which these experiences occurred were not siloed; rather, like life and families, they were a melange of overlapping experiences spread throughout work, school, social and home life and seeking health care.

The experiences described in the theme *living with uncertainty* indicate that uncertainty is an ongoing challenge for people living with a person with MS and aligns with previous research indicating that uncertainty is a key feature of family members' experiences of chronic conditions, including progressive neurological illness.^{85,86}

Tams and colleagues⁸⁶ identify four dimensions where uncertainty is experienced by families of those affected by MS: initial ambiguity about the diagnosis; the typically uncertain diagnosis; the unpredictability of illness course; and how family roles and relationships might be affected over time as MS progresses. These dimensions align with the findings of our review, which also

identified two distinct illness-related temporal dimensions to uncertainty that people living with a person with MS must tackle: the present and the future. There are different challenges for decision-making and planning in each of these time periods.⁸⁵ For example, physical symptoms such as fatigue, mobility and balance issues, and side effects of treatments for the person with MS have practical implications for daily living that may impact planning any or all activities, especially when symptoms are erratic.¹⁵ Future concerns, however, are more focused on disease progression, reduced mobility, ability to have a family, diminishing mental capacity, reduced ability to work and potential economic impacts,¹⁵ which, for people who live with a person with MS, may be framed as concerns about 'anticipated caring'.²³

Rather than eliminate uncertainty, Tams and colleagues⁸⁶ suggest that families can benefit from learning to live with, tolerate and adapt to it. They encourage clinicians working with people affected by progressive neurological conditions (including MS) to use strength-based interventions to help families manage illness-related uncertainty and live well in the face of uncertainty.

Gregory⁸⁷ argues that tasks and activities related to caring and chronic disease management are family practices that form part of the 'ongoing lived experiences of the family relationship'. Furthermore, it is through the incorporation of, and adaptation to, new ways of living into family practices that a feeling of continuity and normality is achieved.⁸⁷ This is especially reflected in the themes *living with uncertainty* and *adapting to life with a person with MS*, where our review found that participants described a sense of normalization as MS was adapted into their everyday lives, creating a 'new normal' in family life, which enabled them to adapt. All five themes identified in our review may be seen to contribute to disruption of ontological security for the person living with a person with MS, creating many life challenges. Participants in studies included in our review described finding difficulty maintaining social connections, seeking emotional and psychological support, living in the present and making sense of their world.

The absence of studies addressing the gendered experiences of people caring for people with MS is striking. The broader caring literature, particularly that from a feminist perspective,⁸³ highlights the fact that caring is predominantly performed by women, and that this has a political dimension, with caring being an undervalued example of 'invisible work'. In the case of MS, which affects many more women than men,⁸⁸ the carer roles are disproportionately taken by men—or at least, the household membership includes high numbers of women with MS and male partners. Expectations of unpaid labour contributed by partners who are outside of, or have left, the paid workforce may play out differently for male family members than for female family members. The lack of research on male carers was also raised in an earlier review of the experiences of spousal caregivers of a person with MS.⁸⁹ However, male participants in the included studies represent those who stayed to act as caregivers, potentially excluding partners who had chosen to leave. There have been mixed findings in studies on partner abandonment among women with MS, with a US study finding female gender of

the person with MS to be a strong predictor of male partners leaving the relationship,⁹⁰ while studies from Denmark⁹¹ and Sweden⁹² found that it was not. Further research in this area is needed to better understand the caring work done by men and how it relates to ideas of masculinity and paid and unpaid work. Research encompassing the gendered experiences of parents of children with MS and children of parents with MS is also needed to address this knowledge gap.

5 | LIMITATIONS

A strength of our study is the inclusion of quality appraisal, which is not a requirement of scoping review approaches.¹⁷ A potential limitation may be the exclusion of quantitative studies, which often provide greater sample sizes and uniformity. This synthesis does not include non-peer-reviewed literature such as personal narratives or reports from advocacy groups. Only studies written in English were included, which resulted in few studies from non-western countries with less developed health care systems, and that may have different cultural expectations of and influences on families.

6 | CONCLUSION

Both the person with MS and the household or family member caring for or living with them often work together in mutual support of personhood. Adapting to life with a person with MS is challenging and requires learning to live with uncertainty and find ways of making sense of one's world through integrating MS into everyday family life and practices. Support services and health care practitioners are currently very much centred on the individual patient. They need to look beyond the person with MS and recognize the relational network of people who surround them and shift their focus to become family- or household-centred. There is a need to design interventions that involve and support the active engagement of decision partners in health care decision-making related to chronic disease, benefitting decision partners, clinicians and patients. Future research and policy foci that are currently underexplored include the experiences of young carers or household family members of people with MS and gendered expectations and performance of carer roles among people living with a person with MS.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Anne Parkinson contributed to conceptualization, methodology, validation, formal analysis, investigation and data curation, writing—original draft and review and editing, visualization and project administration. Crystal Brunoro contributed to conceptualization, methodology, validation, formal analysis, investigation, data curation and writing—review and editing. Jack Leayr contributed to formal analysis and writing—review and editing. Vanessa Fanning contributed to writing—review and editing. Katrina Chisholm contributed to writing—review and editing. Janet Drew contributed to writing—review and editing. Jane Desborough contributed to conceptualization, methodology, investigation, writing—review and editing, supervision and funding acquisition. Christine Phillips contributed to conceptualization, methodology, writing—review and editing, and supervision.

DATA AVAILABILITY STATEMENT

All data generated or analysed during this study are included in this published article and its Supporting Information files.

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