

# Striving to Limit the Impact: Parenting an Adult Child Who Has Multiple Sclerosis—A Grounded Theory Study

Camilla Holden, DClInPsy, MSc, BSc; Peter Hewitt, DClInPsy, BSc; Rachel Tams, DClInPsy, BSc, PGDip

## ABSTRACT

**BACKGROUND:** Multiple sclerosis (MS) is a chronic, progressive autoimmune inflammatory disorder. Its impact is felt not only by individuals but also by their families; however, little is known about the effect on their parents. This study of a cohort from the United Kingdom aimed to develop a conceptual understanding of the parental role and how it changes over time when an adult son or daughter has MS via firsthand accounts.

**METHODS:** Twelve parents of adults with MS were recruited from a UK hospital providing outpatient services to people with MS and a branch of a national MS charity. A social constructivist grounded theory approach informed audio-recorded semistructured interviews and subsequent data analysis.

**RESULTS:** In this sample, parents of adults with MS strove to limit the impact of MS on their son or daughter by undertaking practical caring activities and providing emotional support. The developed theoretical model illustrates how, in their efforts to meet this aim, parents experienced competing demands between prioritizing their child's needs and managing the effects on their life, between managing the emotional experience and protecting their child from the burden of their experience, and between an intensified instinct/desire to help while maintaining their child's independence.

**CONCLUSIONS:** Findings indicate that parents may be uniquely affected by their adult son or daughter having MS, advocating for their inclusion in research and clinical interventions addressing family adjustment to MS. Further research is needed to ascertain the generalizability of these findings in comparable samples and to determine the impact of sociodemographic and cultural variables on the observed phenomena.

*Int J MS Care.* 2023;25(6):259-265. doi:10.7224/1537-2073.2021-053

**M**ultiple sclerosis (MS) is a progressive, autoimmune inflammatory disorder most commonly diagnosed in adults aged 20 to 50 years.<sup>1</sup> Symptoms are wide ranging, and although life expectancy has improved to an average of 75.9 years (compared with 83.4 years among age-matched controls), individuals can experience high levels of accumulated disability, severely impacting quality of life.<sup>2,3</sup>

Difficulties predicting the range of symptoms and rate of progression experienced by individuals<sup>4</sup> require that people with MS and their families adapt to both crises and stable periods while coping with prognostic uncertainty.<sup>5,6</sup> Previous research demonstrates how MS affects the nuclear family. Spouses and children are at greater risk for psychological distress compared with the general population<sup>7-9</sup> and have to adapt to changes in their roles, identity, communication, and belief systems.<sup>10</sup> Thus, in the United Kingdom, national guidelines for the treatment of MS outline that services must consider a patients' family in their plan of care.<sup>11,12</sup>

Despite MS having implications for 3 generations, there is a dearth of research specifically exploring how parents experience having an adult son or daughter with MS. This is surprising considering that, due to age at onset, many individuals with MS are likely to have living parents, and both theoretical and practice-based evidence suggests that understanding how this relationship is or is not impacted by MS may be highly clinically relevant. Literature provided by the leading MS charity in the United Kingdom informs families that MS may interfere with parents' expectations of their adult child's ability to maintain independence. It also details that parents are recognized as important, and appreciated, sources of emotional and practical support to individuals with MS.<sup>13</sup>

The parent to adult child relationship is often overlooked in chronic illness research, although parents consider their role of providing assurance and safety to be lifelong.<sup>14,15</sup> According to life span theories, the parent role is characterized by a

From the Isis Education Centre, Warneford Hospital, Oxford Institute of Clinical Psychology Training, Oxford, UK (CH); and the Department of Psychological Medicine at the Oxford Centre for Enablement, Oxford University Hospitals NHS Foundation Trust, Oxford, UK (PH, RT). *Correspondence:* Peter Hewitt, DClInPsy, Psychological Medicine at the Oxford Centre for Enablement, Oxford University Hospitals NHS Foundation Trust, Windmill Road, Oxford, OX3 7LD, United Kingdom; *email:* Peter.Hewitt@ouh.nhs.uk.

© 2023 Consortium of Multiple Sclerosis Centers.

shifting balance between providing physical and emotional support to offspring and grandchildren,<sup>16</sup> and illness in an adult son or daughter can impact the expected life cycle trajectory of families as it alters parental dependency.<sup>17</sup>

Emerging research into other illnesses indicates how parents are often affected by their child's illness, experiencing negative emotions and a sense of isolation.<sup>18</sup> Importantly, parts of this experience seem to be specific to parents. When comparing spousal caregivers and parent caregivers of an adult with a traumatic brain injury, parents express more intense feelings of grief and sadness related to the loss of who their child was before the injury, in addition to a sense of guilt at not having protected their child.<sup>19</sup>

In MS-specific research, the exact familial relationship of participants is often not specified, and data from multiple relationships are frequently analyzed collectively, inhibiting identification of unique relational processes. For example, the qualitative MS exploration by Bowen, MacLehose, and Beaumont<sup>20</sup> includes parents and finds that as the needs of the individual with MS change, reciprocal changes in relationships are negotiated by family members. Also, adapting to life with MS can lead to "profound insights" into the nature of life and relationships, altering approaches to parenting and grandparenting. However, the study does not make clear which themes can be attributed to which familial relationships.

To our knowledge, no research has been conducted exploring how parents experience their role when their adult child has been diagnosed as having MS. By exploring firsthand accounts from a UK sample, we aimed to understand the role played by a parent to an adult with MS and how the processes of providing practical and emotional support may change over time. We hope to identify some of the specific needs of parents and factors to potentially aid a family's adjustment to living with an MS diagnosis.

## METHODS

### Design

A qualitative research design using a modified constructivist grounded theory (GT) was used to analyze the semistructured interviews.<sup>21</sup> The study protocol was approved by the Nottingham Research Ethics Committee.

### Researcher Context

The principal investigator (C.H.) was a trainee clinical psychologist with experience working with families affected by brain injury. This was their first GT project. They were supervised by 2 clinicians (P.H., R.T.) with experience in GT and working with individuals with MS, as well as academic qualifications in neuropsychology.

### Participants

Participants had a child older than 18 years diagnosed as having MS at least 2 years before the study. Eligible participants were recruited by clinicians working with individuals with MS and their families in acute and rehabilitation

## PRACTICE POINTS



Interviews with 12 parents of 9 adults with multiple sclerosis revealed that the parents' wish to limit the impact of the disease creates competing demands.

These findings underscore the need to inquire about the well-being of parents of people with multiple sclerosis and to provide them with education and support specific to their role and its challenges.

Preparing for the future is an important issue, considering parents commonly worry about reductions in their capacity to care due to aging.

Families may need support to manage the tension between parents' resuming a more active parenting role while also maintaining their child's independence. ■

settings in a UK hospital trust. Parents and children received information about the study when attending routine hospital appointments or through a local MS charity. Potential participants contacted the researcher directly to express their interest, after which a telephone screening appointment was completed to assess eligibility.

Clinicians were asked to approach parents within a range of demographic characteristics and whose offspring were differentially affected by MS to maximize the heterogeneity of the sample. After interview analysis, purposive sampling was used to recruit participants who might offer novel experiences until theoretical saturation was achieved.

### Data Collection and Measures

Guided by an interview schedule developed with MS clinicians, parents were interviewed (range, 45-70 minutes), and these interviews were recorded and transcribed. Questions focused on their experience of parenting and how it may, or may not, have changed over time. They were also asked about the impact of having a child with MS on their own life. In concordance with GT, the schedule was modified during data collection to facilitate the refinement of emerging themes. Participants engaged in a single interview either on hospital premises ( $n = 7$ ) or in participants' homes ( $n = 5$ ) without their partner or child present.

**TABLE. Participant Characteristics**

	Eleanor	Sandra	Heather	Margaret	Kathy	Robert	Shirley	Arthur	Eileen	Henry	Charlotte	Stan
	Couple 1		Couple 2		Couple 3							
Age, y	88	74	68	71	77	79	65	69	70	70	72	70
Sex	F	F	F	F	F	M	F	M	F	M	F	M
Ethnicity	WB	WB	WB	WB	WB	WB	WB	WB	WB	WB	WB	WB
Marital status	WD	MD	MD	MD	MD	MD	MD	MD	MD	MD	MD	MD
Employment status	R	R	R	R	R	R	R	R	R	R	R	R
No. of offspring	3	2	1	1	3	3	3	2	2	2	2	2
Sex of offspring with MS	M	F	F	M	M	F	F	F	F	M		
Age of offspring with MS, y	60	48	40	39	52	40	38	40	40	42		
Years since diagnosis	26	9	9	5	6	2	12	3	12			
MS phenotype	SPMS	PPMS	RRMS	RRMS	PPMS	RRMS	RRMS	RRMS	RRMS	SPMS		
No. of dependents cared for by son/daughter with MS	0	0	2	0	0	2	0	2	0	1		
HADS depression subscale score	12	6	1	0	1	7	5	3	7	0	10	5
HADS anxiety subscale score	10	5	2	6	3	13	11	4	4	1	21	11
Relative Stress Scale score	23	21	3	13	34	34	36	18	15	4	43	25

F, female; HADS, Hospital Anxiety and Depression Scale; M, male; MD, married; PPMS, primary progressive multiple sclerosis; R, retired; RRMS, relapsing remitting multiple sclerosis; SPMS, secondary progressive multiple sclerosis; WB, White British; WD, widowed.

Note: All names are pseudonyms to protect participants' anonymity.

To provide context, participants were asked to complete a demographic data form and 2 self-report questionnaires: the Hospital Anxiety and Depression Scale<sup>22</sup> and the 15-item Relative Stress Scale (RSS).<sup>23</sup>

**Analysis**

The modified constructivist GT data analysis procedure of Charmaz<sup>21</sup> was followed.<sup>24</sup> Initial line by line codes were repeatedly reviewed and grouped into focus codes before theoretical coding, which formed the basis of the final theory. NVivo software (Lumivero) was used for this process. Data saturation was reached after analysis of 12 interviews.

The entire analysis was conducted by the principal investigator. Reflexivity was fostered using a bracketing interview, memo writing, and a reflective journal. Credibility checks to assess the validity of the emerging GT model were incorporated by sharing transcripts, codes, and model reiterations with research supervisors and colleagues experienced in qualitative research.<sup>25</sup>

**RESULTS**

**Participant Characteristics**

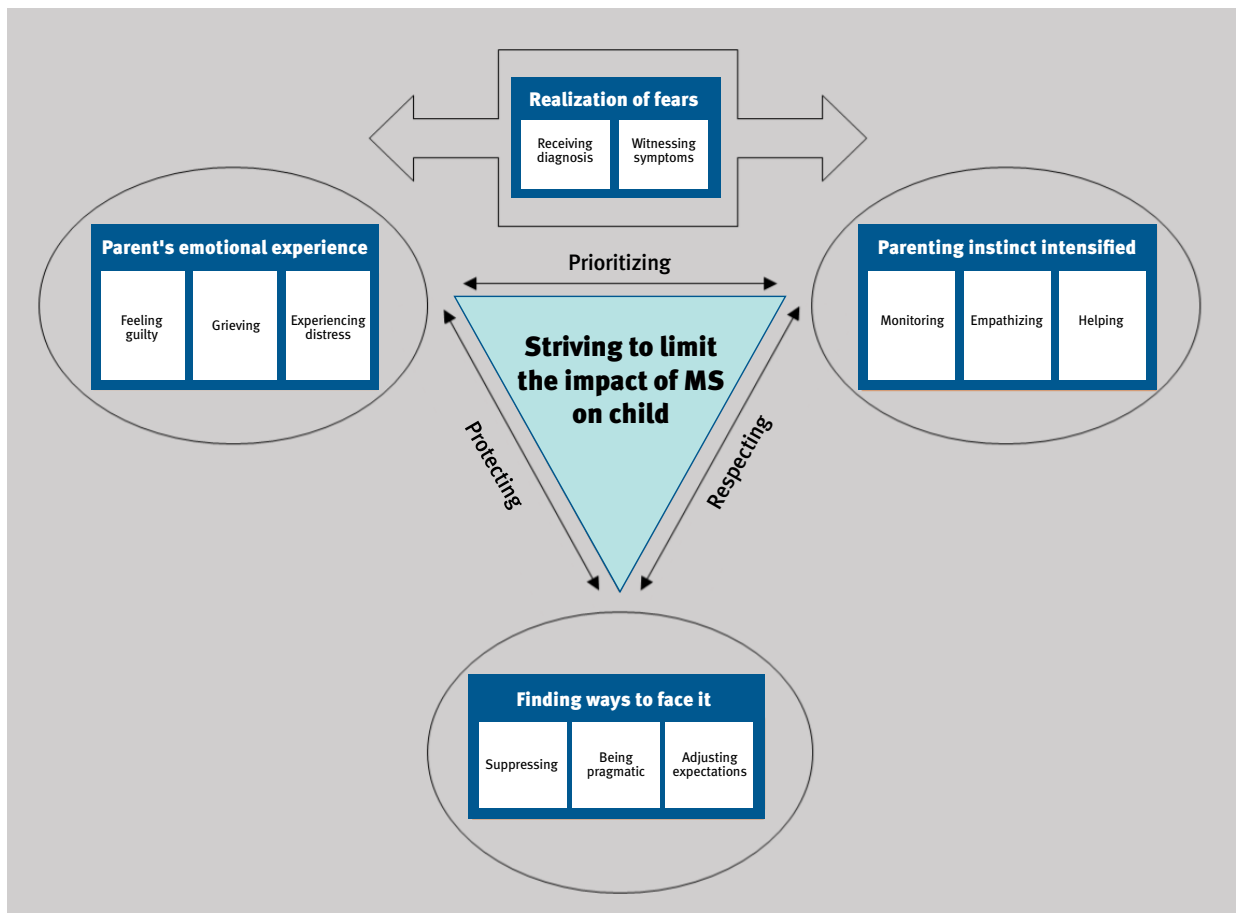
The characteristics of the 12 participants are summarized in **TABLE 1**. Three couples took part in the study, meaning the parents of 9 individuals with MS participated. All participants were White British and were either married

or widowed, with an age range of 65 to 88 years. The mean Hospital Anxiety and Depression Scale depression subscale score was 5 (range, 0-12), and the anxiety subscale score was 7.6 (range, 1-21), both under the clinical cutoff values. One participant's depression subscale score indicated clinically significant symptoms of depression, and the scores of 5 participants indicated clinically significant symptoms of anxiety, suggesting that anxiety is a greater concern. However, only limited conclusions can be drawn, and it cannot be determined whether the scores are directly related to parenting an individual with MS. In all cases where participants' scores were greater than the clinical cutoff, the researcher recommended that they discuss the finding with their doctor. The mean RSS score was 22.4 (range, 3-34). One couple had the same RSS score as each other, and the others varied, suggesting that factors outside of the contextual situation can alter the amount of stress experienced.

**Overview of the Model**

The developed theoretical model in **FIGURE 1** illustrates that for the cohort, the parental role revolves around limiting the impact of MS on their child by providing any needed practical and emotional support. Providing this, parents experience competing demands between prioritizing their child's needs and managing the subsequent effects on their own life; between managing the emotional experience and

Downloaded from http://jmscare.oxfordjournals.org/ by guest on 25 February 2024

**FIGURE 1.** Model of Parents' Experiences

MS, multiple sclerosis.

protecting their child from the burden of their experience; and between an intensified instinct/desire to help and maintaining their child's independence.

### Striving to Limit the Impact of MS on the Child

Participants had an all-encompassing goal to limit the impact of MS on their child by providing any practical (eg, physical care, financial duties) and emotional support necessary and acceptable to their offspring. One mother, Sandra, said, "I think it was just trying to keep her life as normal as it could be given the things that were going wrong with her."

### Realization of Fears

The event of receiving news of a diagnosis or witnessing symptoms appeared to activate parents' fears that their child's well-being may be at risk. The participants were forced to integrate this fear into reality, but struggled to accept this. Shirley said, "When you have a child you think, 'I hope it's going to be OK'; you know, they're not going to be disabled. And I think, 'Well we had 40 years but now I've got a disabled child.' And that's really hard." Heather said, "As

a parent you want to look after them and you would like to take it away, but you can't."

### Parents' Emotional Experience

Participants talked about their distress when witnessing their child's decline and considering that, due to aging, they might not be as capable of providing such intense support in the future. One father, Robert, said, "And I see him walking along and staggering and all the rest of it, and that hurts, it hurts like hell." Margaret said, "But just when he needs, he may need more support and help, the likelihood is that we would not be able to give it to him, whether it's emotional, practical or financial."

Participants grieved the losses experienced by their child as well as the loss of their own envisioned future, including being a grandparent, relishing retirement, and stepping away from some parenting requirements. Further loss included changes to the parent-child relationship such as increased tension due to greater frequency of contact or personality changes resulting from cognitive difficulties. Robert said, "But I don't know what more we could do. If I did, I'd do it. If money would buy...if I had to borrow a

million pounds to do it I'd spend a million pounds and I want my son back, but it's never going to happen."

Participants spoke about feeling guilty that they may have caused the MS and that their own lives continue while their child declines: Stan noted, "...I feel very guilty that he's got MS because I feel somehow responsible. I don't know why that is, but I just feel that...I don't know how he got it. Nobody knows how you get MS, but it could have been something we did; it could be something in my genes I passed on; it could have been something he did when he was a kid. I don't know, but I just feel as though I'm responsible for that for some reason..." Shirley said, "...there's guilt on my part because I am so well. And I hope to be able to continue to be well for the next 20 years, but she can't, and she won't be when she's my age."

### Parenting Instinct Intensified

Participants were unanimous in their view that their role as a parent is lifelong. In the context of MS, these parenting instincts intensified, resulting in intensive monitoring of well-being and subsequent development of a detailed understanding of their child's symptoms and potential triggers. Parents were driven to increase contact either in person or using technology to be responsive to their child's needs, to alleviate their own worry, and to help them to continue to empathize with their child's situation. Shirley said, "...for my own piece of mind, [I] just...need to know that she's okay...emotionally and whether she's hurting too much because it does get her down."

Participants spoke about continually considering how to help and appeared to exhaust all the available options. Eleanor said, "It's not easy because all the time you're thinking what can you do to help? Are you doing the right thing? Is there anything else one can do?"

### Prioritizing the Child

Despite being negatively emotionally impacted, parents consistently prioritized their child's needs over their own to limit the impact of MS. Consequently, they experienced restrictions on their own lives, which they accepted willingly, although the losses were at times linked with increased sadness. Participants described feeling guilty if they did consider their own needs. Arthur said, "...and then generally feeling, if you do feel sorry for yourself, there's this feeling of guilt because you're not the one with MS so what's the problem, you know?"

### Protecting

Parents made a conscious decision to shield their own emotional experience and problems from their child as they believed sharing would increase their burden, conflicting with their desire to limit the impact of MS. Margaret said, "I've learned it over time. I'm a dribbly heap now, but when he first told me I could not talk about it. At all. Because I'm just tearful. And he didn't want to see me tearful. It certainly didn't help him. But that did get better over the first year.

Although I'm tearful now with you, I wouldn't be tearful with [my son]." Shirley shared, "And if I'd got a problem I wouldn't, naturally, talk to [my daughter] about it which I would have done in the past because she's got enough to cope with." Unfortunately, by withholding their concerns, parents grieved the close relationship they had with their children before their diagnosis. They had to find ways of coping alone.

### Finding Ways to Face It

The way in which parents coped shifted over time. Most reported an inability to resolve grief, due to the knowledge that MS is progressive. Therefore, parents tried suppressing difficult emotions and, being pragmatic, this intensified their desire to help. Sandra said, "Up and down, you never knew what was going to happen from one day to the next, so you have to be on your top guard, or more, but just expecting anything, you know. And face it when it comes." Eleanor said, "And I have got to, you know, face it and just do things to help, and very little, but what I could do."

Many participants seemed to adjust their expectation over time. For some, initial hope wavered after witnessing successive relapses and decline, forcing them to accept the reality of MS. To manage the reality, they worked on focusing on what they did have and appraising the situation as having the potential to be worse. Although accepting the reality could relieve frustration and guilt, it could simultaneously increase distress as parents recognized their child might have more disability in the future: Kathy said, "Knowing that it's going to get worse is the hardest thing to cope with. Knowing that it's not really going to get much better at all."

### Respecting Independence

A primary challenge was how to monitor and help without being intrusive or interfering, a conflict between parents' goals to limit the impact of MS (inclusive of maintaining independence), to help, and to know how their children were faring. Participants seemed to be conscious of this dilemma and aware of the tension that could ensue if the balance was not maintained. Parents devised strategies such as pacing contact and finding less obvious, more informal ways to learn about their welfare. Margaret said, "Enough distance not to be interfering and ringing daily and saying 'Are you all right?' Cause I don't. We [have] casual contact often enough for me to be able to keep my finger on the pulse, and that's why I notice when he's not responding to something I would expect him to, or I have not had a text giving me a link to a website about something." Shirley said, "[It helps i]f you can have an informal meet-up like we do, and a reason for it, rather than just going round and saying 'Oh, what do you need doing?'"

Participants also consciously took the lead from their child, helping where "allowed" or suggesting that helping would not add additional burden. Heather said, "...if she needs groceries or something when I'm down I'll say, 'I'm going out. Shall I get this for you? Write a list.' And yeah,



she'll sort of, 'Oh if you're going out could you get me this? Could you get me that?' so she hasn't got to go and do it. But I said I'm going out, so I volunteered."

## DISCUSSION

This study of a cohort in the UK investigated the role of a parent to an adult with MS and how it may change over time. Parents in this study believed that their role was a lifelong commitment and merely intensified in response to illness, contradicting sequential models of parenting where transition to subsequent stages is determined by age.<sup>16</sup> Rather, this "reawakening of parental nurturing," also identified in the parents of adults diagnosed as having cancer,<sup>26</sup> advances a model of parenting that is responsive to need irrespective of the age of either party, suggesting that parents could be a substantial resource for families adapting to adversity related to chronic illness, as already documented in practice-based evidence.<sup>13</sup>

Participating parents disclosed distress and grief at the changes in the quality of their relationship with their child. This concurs with research reporting self-rated relationship quality to be a significant predictor of distress in spouses of individuals with MS.<sup>27</sup> In the spousal relationship, the perceived quality is evidently linked to feeling differentially impacted by MS and each taking different approaches to problems.<sup>28</sup> Findings from this study suggest cognitive and personality changes in the individual with MS as potential mediating factors for the parent-adult child relationship, along with the parent withholding feelings and concealing problems, reducing the authenticity of their connection. This reduced connectedness may also result in the parent and child using different problem-solving strategies.

Evidence suggests that when couples living with MS adopt a joint approach to facing its consequences, a sense of togetherness is fostered, strengthening their belief in their joint and individual ability to cope with difficult periods.<sup>29</sup> This indicates that the parents in this study may actually be undermining their efforts to limit the impact of MS by increasing the disconnect between their child's experience and their own. Facilitating a shared approach to facing MS may be an intervention target for improving family adjustment. Further research is needed to explore the extent to which these factors apply to wider populations and the scope for intervention.

Participants' drive to help was further bolstered by suppressing emotions and facing the situation pragmatically to cope with their own feelings of possibly being intrusive and impeding their child's independence. This dilemma is acknowledged by Rolland,<sup>17</sup> who proposes that a sudden increase in dependence on parents can threaten the level of individuation of both parent and child.

Parents in this study devised strategies to monitor welfare and provide help without being intrusive, such as pacing contact and informally inquiring about well-being. These strategies were honed over time with the aim of completing them without detection to keep life as normal as possible and to avoid communication being dictated by MS.

Having limited options available to cope, parents spoke candidly as they envisioned no good resolution to the situation and, consequently, to their own distress. Consistent with other life cycle research,<sup>16</sup> some participants made explicit reference to leaving the expected life cycle pathway. Opening dialogues about these concerns may help families plan for increasing limitations in parents' resources (due to aging) and relieve parents of some distress.

Participants frequently articulated a conscious decision to suppress their feelings and face the situation pragmatically, managing emotions and ensuring their dependability. They believed that this allowed them to protect their child, but in some cases this seemed to lead to a lack of situational acceptance. In contrast to suppression,<sup>30</sup> reappraisal of emotions is an advantageous strategy for emotional regulation, and helping parents access and discuss their emotions may reduce psychological distress.

The inclusion in this study of multiple MS subtypes and disease durations of 2 to 22 years provides tentative evidence for the study findings to apply to parents across an extended period of their MS journey, highlighting the importance of considering parents' needs at all points of contact with services.

A clear limitation of this study is the narrow nature of the sample across other dimensions, which, along with the chosen qualitative method, places significant limitations on the generalizability of the findings. This study does provide a theoretical base from which to explore emerging hypotheses in a previously neglected population. Further research is needed to develop and shape the emerging hypotheses and to explore the ways in which they are influenced by sociodemographic and cultural variables. Currently, it cannot be determined whether the identified processes sufficiently represent the views of those who share comparable demographics or the experiences of younger, employed, non-White British, and single parents of individuals with MS.

Note that there may have been a selection bias during recruitment, with the cohort being motivated to tell their stories. It is possible that the experiences of less affected parents have not been captured as they may have been less motivated to participate. This would lead to an overestimation of the effect on parents.

By only interviewing parents, their narrative is at the forefront of the study. However, future research would benefit from interviewing the person with MS to gain their view on being parented, specifically their experience of the balance between autonomy and support. In addition, including individuals with MS would provide them with an opportunity to share their views about how a parent could be most helpful to them, ensuring that parents' personal resources are targeted where they can be of most benefit.

The results of this study indicate a value to MS services routinely asking individuals with MS whether their parents are involved in supporting them and to offer the choice to invite parents to appointments. This would provide clinicians with an opportunity to ask about parental caring

responsibilities, well-being, and relational issues, such as reduced emotional connectedness. This may help clinicians to support key relationships, facilitating adjustment to adversity.<sup>31</sup> This family approach would be in line with the National Institute for Health and Care Excellence guidelines that advise that the frequency of contact with individuals with MS will be dependent on both their own needs and the needs of their family.<sup>12</sup>

Several parents reported feelings of isolation and clinically significant levels of anxiety and stress. Routine screening and signposting for psychological support for anxiety, depression, and stress management may improve the well-being of this group and, subsequently, the well-being of the family system.

This is a unique study within MS literature and contributes to a relatively small body of research investigating parenting an adult child. The findings have helped shape a hypothesis about how, as a result of an MS diagnosis, parents experience changes to their roles and how they may be impacted differently compared with other family members. By involving parents in MS services, clinicians may be able to improve family adjustment to MS and identify parents at risk for psychological distress. Future directions for research include expanding the study of parent–adult child relationships in MS and other chronic neurologic diseases and consideration of the impact of sociodemographic and cultural variables. ■

**ACKNOWLEDGMENTS:** We express gratitude to all the participants who took part in the study. Their openness, care, and willingness to help has been a huge source of inspiration to us as clinicians, researchers, and fellow human beings. We also thank the academic team at the Oxford Institute of Clinical Psychology Training and Research for reading and commenting on draft manuscripts.

**FINANCIAL DISCLOSURES:** The authors declare no conflicts of interest.

**FUNDING/SUPPORT:** None

**PRIOR PRESENTATION:** Presented at Grand Rounds, Oxford Centre for Enablement; September 2018; Oxford, United Kingdom.

## REFERENCES

- Mackenzie I, Morant S, Bloomfield G, MacDonald T, O'Riordan J. Incidence and prevalence of multiple sclerosis in the UK 1990–2010: a descriptive study in the General Practice Research Database. *J Neurol Neurosurg Psychiatry*. 2014;85(1):76–84. doi:10.1136/jnnp-2013-305450
- Confavreux C, Vukusic S, Adeleine P. Early clinical predictors and progression of irreversible disability in multiple sclerosis: an amnesic process. *Brain*. 2003;126(pt 4):770–782. doi:10.1093/brain/awg081
- Marrie RA, Hanwell H. General health issues in multiple sclerosis: comorbidities, secondary conditions, and health behaviors. *Continuum (Minneapolis)*. 2013;19(4 multiple sclerosis):1046–1057. doi:10.1212/01.CON.0000433284.07844.6b
- Kasser SL, Goldstein A, Wood PK, Sibold J. Symptom variability, affect and physical activity in ambulatory persons with multiple sclerosis: understanding patterns and time-bound relationships. *Disabil Health J*. 2017;10(2):207–213. doi:10.1016/j.dhjo.2016.10.006
- Rolland JS, Walsh F. Facilitating family resilience with childhood illness and disability. *Curr Opin Pediatr*. 2006;18(5):527–538. doi:10.1097/01.mop.0000245354.83454.68
- Birnbaum GL. *Multiple Sclerosis: Clinician's Guide to Diagnosis and Treatment*. Oxford University Press; 2013.
- Aronson KJ. Quality of life among persons with multiple sclerosis and their caregivers. *Neurology*. 1997;48(1):74–80. doi:10.1212/wnl.48.1.74
- Pakenham KI, Cox S. The nature of caregiving in children of a parent with multiple sclerosis from multiple sources and the associations between caregiving activities and youth adjustment overtime. *Psychol Health*. 2012;27(3):324–346. doi:10.1080/08870446.2011.563853
- Razaz N, Nourian R, Marrie RA, Boyce WT, Tremlett H. Children and adolescents adjustment to parental multiple sclerosis: a systematic review. *BMC Neurol*. 2014;14(1):107. doi:10.1186/1471-2377-14-107
- Tams R, Prangnell SJ, Daisley A. Helping families thrive in the face of uncertainty: strengths based approaches to working with families affected by progressive neurological illness. *NeuroRehabilitation*. 2016;38(3):257–270. doi:10.3233/NRE-161317
- National Service Framework for Long Term Conditions. Department of Health and Social Care. March 10, 2005. Accessed February 24, 2020. <https://www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions>
- Multiple sclerosis in adults: management. National Institute for Health and Care Excellence. Updated November 11, 2019. Accessed February 26, 2020. <https://www.nice.org.uk/guidance/cg186>
- Living with the effects of MS. MS Society UK. Accessed August 28, 2016. <https://www.mssociety.org.uk/sites/default/files/Livingwiththeeffects2016.pdf>
- Levitzi N. Parenting of adult children in an Israeli sample: parents are always parents. *J Fam Psychol*. 2009;23(2):226–235. doi:10.1037/a0015218
- Del Corso AR, Lanz M. Felt obligation and the family life cycle: a study on intergenerational relationships. *Int J Psychol*. 2013;48(6):1196–1200. doi:10.1080/00207594.2012.725131
- McGoldrick M, Garcia Preto NA, Carter BA. *The Expanding Family Life Cycle: Individual, Family, and Social Perspectives*. Pearson; 2015.
- Rolland JS. *Families, Illness, and Disability: An Integrative Treatment Model*. Basic Books; 1994.
- Van Humbeeck L, Piers R, Dillen L, Verhaeghe S, Van Den Noortgate N. Older parents' experiences following a serious illness trajectory of an adult child: a review of the literature and recommendations for future research. In: *Proceedings of the 8th Congress of the European Union Geriatric Medicine Society (EUGMS)*. European Academy of Neurology; 2012:5134–5135.
- Kratz AL, Sander AM, Brickell TA, Lange RT, Carlozzi NE. Traumatic brain injury caregivers: a qualitative analysis of spouse and parent perspectives on quality of life. *Neuropsychol Rehabil*. 2017;27(1):16–37. doi:10.1080/09602011.2015.1051056
- Bowen C, MacLehose A, Beaumont J. Advanced multiple sclerosis and the psychosocial impact on families. *Psychol Health*. 2011;26(1):113–127. doi:10.1080/08870440903287934
- Charmaz K. *Constructing Grounded Theory*. Sage Publications; 2014.
- Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983;67(6):361–370. doi:10.1111/j.1600-0447.1983.tb09716.x
- Greene J, Smith R, Gardiner M, Timbury G. Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: a factor analytic study. *Age Ageing*. 1982;11(2):121–126. doi:10.1093/ageing/11.2.121
- Glaser BG. *Basics of Grounded Theory Analysis: Emergence vs. Forcing*. Sociology Press; 1992.
- Roubal J, Rihacek T. Therapists' in-session experiences with depressive clients: a grounded theory. *Psychother Res*. 2016;26(2):206–219. doi:10.1080/10503307.2014.963731
- Van Humbeeck L, Dillen L, Piers R, et al. Tightrope walkers suffering in silence: a qualitative study into the experiences of older parents who have an adult child with cancer. *Int J Nurs Stud*. 2015;52(9):1445–1453. doi:10.1016/j.ijnurstu.2015.05.010
- Pakenham KI. Coping with multiple sclerosis: development of a measure. *Psychol Health Med*. 2001;6(4):411–428. doi:10.1080/13548500126537
- Starks H, Morris MA, Yorkston KM, Gray RF, Johnson KL. Being in-or out-of-sync: couples' adaptation to change in multiple sclerosis. *Disabil Rehabil*. 2010;32(3):196–206. doi:10.3109/09638280903071826
- Boland P, Levack WM, Hudson S, Bell EM. Coping with multiple sclerosis as a couple: 'peaks and troughs'—an interpretative phenomenological exploration. *Disabil Rehabil*. 2012;34(16):1367–1375. doi:10.3109/09638288.2011.645115
- Nezlek JB, Kuppens P. Regulating positive and negative emotions in daily life. *J Pers*. 2008;76(3):561–580. doi:10.1111/j.1467-6494.2008.00496.x
- Walsh F. *Strengthening Family Resilience*. Guildford Publications; 2015.