Received: 7 January 2019 | Revised: 20 June 2019 | Accepted: 9 July 2019

DOI: 10.1111/hsc.12822

ORIGINAL ARTICLE

Health and Social Care in the community WILEY

On the path together: Experiences of partners of people with multiple sclerosis of the impact of lifestyle modification on their relationship

Sandra L. Neate MBBS, FACEM[1] | Keryn L. Taylor MBChB, FRANZCP[1,2] | George A. Jelinek MD, FACEM[1] | Alysha M. De Livera BSc, PhD[1] | Steve Simpson, Jr MPH, PhD[1] | William Bevens BSc, MBSc[1] | Tracey J. Weiland BBSc(Hons), PhD[1]

[1]Neuroepidemiolgy Unit, Melbourne School of Population and Global Health, University of Melbourne, Melbourne, Vic., Australia

[2]Department of Psychiatry and Psychosocial Cancer Care, St Vincent's Hospital, Melbourne, Vic., Australia

Correspondence
Sandra Leanne Neate, Neuroepidemiology Unit, Melbourne School of Population and Global Health, University of Melbourne, 207 Bouverie Street, Carlton, VIC 3010, Australia.
Email: sandra.neate@unimelb.edu.au

Funding information
This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors. The Neuroepidemiology Unit is supported by philanthropic donations from Linda and Tony Bloom and Mr Wal Pisciotta.

Abstract

Multiple sclerosis (MS) has a major impact on the relationship of couples living with the illness. Although some positives of dealing with MS as a couple have been identified, MS has been associated with higher rates of relationship breakdown and worse Quality of Life (QOL) for both people in the relationship, especially if the person with MS experiences a decline in mental or physical health or develops disability. Modification of lifestyle-related risk factors has been associated with improved outcomes for people with MS, including physical and mental health-related QOL, and these improved outcomes may lead to improved experiences for their partners. We aimed to explore the perspectives and experiences of the partners of people with MS, when the people with MS had undertaken an intensive residential workshop regarding healthy lifestyle, to understand the impact of MS and lifestyle modification on these partners' experiences of their relationship. Within the framework of Heidegger's interpretive phenomenology, semi-structured interviews were thematically analysed. Participants were in a spousal relationship with people with MS who had attended an intensive residential workshop regarding modification of lifestyle-related risk factors between 2002 and 2016. Participants lived in Australia, New Zealand, the United Kingdom and Europe. Three major themes were identified relating to the couple's relationships: providing support, remaining connected and togetherness. Aspects of these themes, not commonly previously reported, included the personal and relationship benefits experienced from providing support with lifestyle modification, improved communication, and the resultant greater sense of closeness. These experiences of partners of people with MS improve our understanding of both the complexities of living with MS and adopting lifestyle modification, and suggest some potential benefits to relationships.

KEYWORDS
lifestyle modification, multiple sclerosis, partners, qualitative, relationships

1 | INTRODUCTION

When a spousal partner has multiple sclerosis (MS), a demyelinating disease of the central nervous system with an unpredictable clinical course, navigating intimate relationships may be both challenging and rewarding. Couples dealing with MS have identified positive outcomes for their relationship, such as personal growth through facing adversity and other challenges together (Ackroyd et al., 2011). Couples identified personal growth as a benefit of living with MS and that each partner's growth depended on the other, an indication that couples search for and find meaning together (Ackroyd et al., 2011). Partners in caring roles described strengthening of relationships in general as a positive outcome (Pakenham, 2005b).

MS nonetheless poses challenges for partners and couples. Partners may experience anxiety, fear and uncertainty about the diagnosis (Bogosian, Moss-Morris, Yardley, & Dennison, 2009; Strickland, Worth, & Kennedy, 2015), potential changes to their roles and relationships, and the prospect of becoming a carer (Strickland et al., 2015). Deterioration in partners' Quality of Life (QOL) may occur if the people with MS (PwMS) experience physical or mental health decline (Aronson, 1997; D'Alisa et al., 2006; Gottberg et al., 2014; Hakim et al., 2000) or develop disability or cognitive impairment (Figved, Myhr, Larsen, & Aarsland, 2007).

Although not all studies agree (Hakim et al., 2000), evidence suggests that couples have a decreased likelihood of remaining in the relationship over time compared with the general population (Pfleger, Flachs, & Koch-Henriksen, 2010). Indeed, associations exist between level of disability and being divorced or separated; men, with severe disability being four times as likely and women with severe disability being twice as likely to be divorced or separated compared to those with little disability (Hammond, McLeod, Macaskill, & English, 1996). Couples perceived that their relationship quality decreased over time (Samios, Pakenham, & O'Brien, 2015), and others reported that MS had a negative impact on their relationship (McCabe & McDonald, 2007). When partners were in care-giving roles, both members of the partnership experienced poorer QOL (Aronson, 1997).

The health and well-being of PwMS influences the physical and mental health-related QOL (HRQOL) of their partners (Aronson, 1997; Figved et al., 2007; Gottberg et al., 2014) and affects their intimate relationships (Hammond et al., 1996; McCabe & McDonald, 2007; Pfleger et al., 2010; Thormann et al., 2017). Therefore, factors affecting the health of PwMS play an important role in the life of the partner and the couple. Increasingly, there is evidence of associations between modification of lifestyle-related risk factors and improved mental and physical health outcomes in MS (D'Hooghe, Nagels, Bissay, & De Keyser, 2010; Fitzgerald et al., 2018; Hempel et al., 2017; Jelinek et al., 2016; Levin et al., 2014; Marck et al., 2014). PwMS who attended an intensive residential workshop regarding evidence-based lifestyle interventions reported improved HRQOL 5 years post-intervention (Hadgkiss, Jelinek, Weiland, Rumbold, et al., 2013; Li et al., 2010). In a subset with more complete data, PwMS reported improved HRQOL, reduced self-reported doctor-diagnosed relapse rate, and stabilised disability assessed by the Multiple Sclerosis Impact Scale Physical Component (MSIS-20), at one and 3 years post-intervention (Marck et al., 2018).

Importantly, these data contrast with the general decline in health and HRQOL in the wider MS population (Chruzander et al., 2014). Both MS and intensive lifestyle modification likely have significant influences on intimate relationships, but this has not been previously described. The impact of lifestyle modification beyond health outcomes, such as impacts on partners and the couple's relationship, has not been explored. The aim of this study was to interview partners of a subset of PwMS, that is, PwMS who had attended a workshop advocating major lifestyle modification, to explore their experiences of the impact of MS and lifestyle modification on their intimate relationship.

What is known about this topic

- Negative relationship outcomes for couples living with multiple sclerosis (MS) are well known.
- Quality of life for both partners may deteriorate if the person with MS experiences health decline.
- Positive partner experiences are less commonly reported and include benefit finding and growth through adversity.

What this paper adds

- For people with MS who undertake lifestyle modification, benefits may be experienced by the partner and the couple.
- Benefits are obtained through making major changes together, working with unity of purpose towards goals, improved communication and a resultant sense of closeness and togetherness.
- Clinicians working with couples with MS should consider the potential benefits of positive lifestyle modification to couples.

2 | MATERIALS AND METHODS

2.1 | Study design

Heidegger's interpretive phenomenology guided the study (Horrigan-kelly, Millar, & Dowling, 2016). Heidegger's philosophy explores the meaning of what it is to be human and experience life in the context of time and place where the person is always within, rather than separate from, their experiences (Dibley, Williams, & Young, 2019). This philosophy informs a methodology where the participants' experiences do not occur in isolation and the researcher, with their own experiences, assumptions and prejudices, is thus a necessary part of the research methodology.

2.2 | The workshop

The residential workshop is for PwMS and their support people, including partners, if present. The evidence-based interventions are described in Table 1. The information is delivered by several modalities: evidence-based interactive lectures; practical food workshops; theory and practice of meditation; and facilitated couple and group-based activities. There are also opportunities for building connections outside of formal sessions including evening organised group activities and relaxation.

2.3 | Data collection

Interviewees were partners of PwMS who had attended a workshop; they were purposively sampled using a secondary recruitment strategy from an existing research dataset. The dataset, the Health Outcomes and Lifestyle In a Sample of people with MS (HOLISM) dataset, is an international sample of 2,466 PwMS (Hadgkiss, Jelinek, Weiland, Pereira, et al., 2013). Of these, 345 PwMS had attended a workshop in Australia, New Zealand, the United Kingdom, or Europe between 2002 and 2016 (Marck et al., 2018). Of these, 280 were partnered. These 280 people were electronically randomised and then sequentially contacted by email as described below.

PwMS were asked to forward the email to their partner, this email containing an explanation of the study and an invitation to participate. Following the invitation link led to a participation survey querying their interest in participating. A 'no' response ended the survey while 'yes' led to a request for informed consent, and queried demographic data, and questions regarding whether the invitee had attended the workshop and names of workshop facilitators.

Invitations were sent in groups of 10 and, following completion of interviews, a further 10 invitations were sent. Interview numbers were not predetermined. Further purposive sampling ensured sufficient female partners were interviewed. Sampling ceased when researchers felt little new was emerging from interviews and apparent data saturation had occurred (Saunders et al., 2018), while acknowledging that experiences may have existed that were not described in this study.

Participants were required to speak English and be in a spousal relationship with PwMS who had attended a workshop. There was no requirement that the participant had attended the workshop.

Two female specialist medical practitioners (SN and KT), who had facilitated workshops independently, conducted the interviews. The interviewers had over 40 years combined clinical experience and extensive experience conducting clinical and research interviews. Researchers believed knowledge of the workshop would be advantageous to the study, assist with participant rapport and be consistent with Heidegger's philosophy where researchers' experiences are a legitimate component of the research (McConnell-Henry, Chapman, & Francis, 2011). However, researchers were mindful that participants may express opinions more openly if not talking with the facilitator of the workshop which they and/or their partner attended. Therefore, a non-facilitator researcher made contact to arrange and conduct interviews.

TABLE 1 The lifestyle risk factors and recommended modifications addressed at the workshop

Lifestyle risk factor	Recommended modification
Diet	Plant-based whole food diet, ultra-low saturated fat, plus seafood, with plant-based omega-3 supplementation
Exercise	Regular vigorous exercise of 30 min duration
Stress reduction	Daily meditation or other stress reduction technique
Vitamin D	Regular sun exposure at defined safe levels or vitamin D supplementation
Smoking	Smoking cessation

The researchers wished to explore whether undertaking lifestyle modification affected partners' experiences but little has been written regarding the impact of lifestyle modification on couples to inform question development. An interview schedule was designed by the researchers to understand the effect of MS and lifestyle modification on the partners' life, relationship and view of the future (Appendix S1). Interview questions were broad and allowed the participant to elaborate and clarify.

Consent to participate was confirmed. Interviews were conducted between July and October 2016, via telephone or Skype by interviewers located in Melbourne, Australia and participants located in their homes. Interviews ranged from 20 to 62 min (average 36 min). Time since attendance at retreat varied from 1 to 10 years. Interviewers reviewed the initial four recordings together and were satisfied the interviews were being conducted similarly. No changes to technique or interview questions were required.

2.4 | Data analysis and reporting

The researchers used a hermeneutic interpretive process to analyse and interpret the data (Crist & Tanner, 2003). Two researchers (SN and KT) acknowledged assumptions and preconceptions and performed the initial analyses (McConnell-Henry et al., 2011). The interpretive team (SN, KT and TW) met frequently and narratives were examined simultaneously with development of emerging themes. The team added insight through debate and discussion (McConnell-Henry et al., 2011). Interviews continued between meetings.

Four overarching themes were identified. Each was then considered separately and transcripts were re-analysed, providing new understandings not apparent at the time of initial analyses (Ironside, 2006). This study reports one of the overarching themes, 'On the path together', and reflected participants' experiences regarding their relationship as a couple.

Although computer-assisted qualitative data analysis software is not commonly employed in hermeneutic studies, we used NVivo software to sort and manage data once the interpretive processes were complete. Quotations are verbatim other than deletions of

words unnecessary for meaning, indicated with '…'. The workshop is at times called 'the retreat'. The participant's research number (P...) and sex (F, M) follow the quotation. Evidence for adherence to the COnsolidated criteria for REporting Qualitative research (COREQ) checklist is attached (Appendix S2).

2.5 | Rigour and trustworthiness

Interviews were audio recorded, transcribed de-identified by an independent transcription company and stored in password-protected files. SN compared recordings with transcripts to ensure accuracy. Researchers were deeply involved with participants during the interview, resulting in a co-constituted understanding of experience. The researcher—participant relationship provides it's own credibility, thus negating the need to confirm the already agreed understanding by returning manuscripts to participants. Member checking to confirm the 'accuracy' of the researcher's interpretation is thus contradictory to the philosophy which underpins the research methodology (McConnell-Henry et al., 2011).

The involvement of multiple researchers in analysis (SN and KT) and frequent reflective discussions (SN, KT and TW) (Sandelowski, 1986) also enhanced credibility. Verbatim extracts were used to enhance transparency (Beck, 1993) enabling readers to assess validity of interpretations. Records of researcher meetings and sequential drafts of coded data were retained to demonstrate how themes emerged and evolved (Nowell, Norris, White, & Moules, 2017). Reflexivity (Clancy, 2013) was ensured by self-reflection and documentation of decision-making and reflections in meetings.

3 | RESULTS

3.1 | Participants

Of 103 email invitations sent, 20 (19%) were declined, 59 (57%) received no response, 24 (23%) acceptances were received but three (3% of total) of those were unable to be contacted to arrange an interview. Twenty-one (20%) interviews were conducted. Characteristics of participants are described in Table 2. The majority (71%) were male, 57% were aged greater than 50, and over half (52%) had been in a relationship for more than 20 years. Approximately half (52%) had attended the workshop with the person with MS. Most partners (62%) were employed. All relationships in the interviewed sample were heterosexual. Partners reported characteristics of the PwMS (Table 3).

TABLE 2 Characteristics of participant (*N* = 21)

Variable (participant)	Category	Number (%)
Sex	Male	15 (71)
Age (years)	20–29	3 (14)
	30–39	2 (10)
	40–49	4 (19)
	50–59	3 (14)
	60–69	7 (33)
	70–79	2 (10)
Attendance at workshop	Yes	11 (52)
Years of relationship	1–10	7 (33)
	11–20	3 (14)
	21–30	4 (19)
	31–40	2 (10)
	41–49	4 (19)
	50 or more	1 (5)
Employment status	Part/full time	13 (62)
	Retired	6 (28)
	Unable to work	1 (5)
	Maternity leave	1 (5)

TABLE 3 Characteristics of person with multiple sclerosis (reported by partner)

Variable	Category	Number (%)
Type of MS	RRMS	7 (33)
	Progressive MS	6 (29)
	CIS	1 (5)
	Unsure	7 (33)
Years since diagnosis	0–5	6 (29)
	6–10	8 (37)
	11–20	6 (29)
	21–40	0 (0)
	>40	1 (5)
Disability	No	16 (76)
	Yes	5 (24)
Years since workshop	1–2	5 (24)
	2–5	7 (33)
	>5	9 (43)

Note: Disability question: 'Has the person with MS used a walking aid in the last 6 months?' Type of MS was as described by the partner from recollection.
Abbreviations: CIS, clinically isolated syndrome; MS, multiple sclerosis; RRMS, relapsing remitting MS.

3.2 | Themes

As part of a larger study exploring the effect of MS and lifestyle modification on the partner's life, relationship and view of the future, this study—'On the path together'—named by researchers to reflect the overall sense of participants' experiences, examined partners' perspectives regarding the impact that MS and lifestyle modification had on their relationship as a couple. The three main themes that emerged from the data were:

1. Providing support
2. Remaining connected

3. Togetherness.

3.2.1 | Providing support

Partners provided support to the PwMS in both practical and emotional ways. Some partners provided encouragement for the person in their physical endeavours to improve their health and the opportunity for the person to undertake these challenges:

> We just try and support him - like it's really important and makes him really happy to run a lot and be very active. I love all of that, I love going to support him. (P20, F)

Making dietary changes along with the person was often the most tangible support they could provide, and partners found making these changes was a way of nurturing their relationship. They considered the potential challenges if the person had attempted major lifestyle modification, especially significant dietary change, without their support. Some partners who had attended the workshop had discussed this issue with other partners and had made their decisions to adopt the changes along with the person with MS. They saw this support as vital to success in attempting lifestyle modification:

> Through the week, hearing the conversations, the people that were there without their partners, hearing the stories of how difficult they found it having to cook their favourite meal of steak and chips for their husband before then making up a salad that they didn't want. It made me want to cry. So how are they ever going to be successful with the lifestyle change when they're having to live that. I know that that was one extreme but my advice would be try and, as a supportive partner, try and be as close to the living it with your partner. (P21, M)

Some reflected later, having kept in contact with other partners that this type of support may have contributed to the strength of their relationships, and they were concerned that others' relationships may have suffered without this support:

> I mean the main thing was…when we had the retreat I just committed myself to it, which was an issue that came up with the support partners when we had our separate meeting. There was a big discussion about whether they could…be involved in that. From the follow-up, friends we had at the retreat, some of them have split up because of MS. (P18, M)

Partners reflected that, by providing this kind of support, any sense of facing the challenges of MS alone could be lessened, and that making these choices together enhanced their relationship:

> When we did it together - [partner] didn't ever feel sorry for himself, that sounds terrible, but he didn't. He doesn't have to do this but then it was made easier by the fact that I was choosing to do it with him, especially because we're overseas and we only really have each other (P7, F)

Some PwMS only required the psychological support of their partner, often coupled with the partner managing life's practicalities of the household and family, allowed the person the freedom to undertake whatever they considered necessary for their health:

> Then she'll [probably do that] by herself and bat on. No need to involve me. She might just say, this is what I want to do, or this is what's happening, and yeah I'll just look after the home fires. (P11, M)

For others, finding the balance between providing the support in a manner acceptable to both, allowing space and encouraging independence was challenging. Some partners described how their support was at times rejected or their offer of support was perceived as being overprotective and not allowing independence, causing confusion regarding how to be helpful and, at times, a sense of hurt by the rejection of their efforts:

> I'll often help and that usually gets pushed away. (When that happens I just) keep out of her way. (P11, M)

Others felt they struggled to provide support in a way that was beneficial in the longer term. They were concerned about taking too much responsibility when it may have been more expedient to do so, and therefore not encouraging independence:

> What I'm trying to do at the moment, and it is difficult because it saves time if I just continue doing what I'm doing, but I'm trying to step back and let him do things for himself because I don't want him to become someone who is used to me doing everything. That's not going to help him get better. (P20, F)

3.2.2 | Remaining connected

This theme reflected how partners experienced and dealt with the challenges of sustaining their relationship. MS presented unique challenges to their relationship such as the need to understand emotions, moods and behaviours of the PwMS that had not been present previously and developing communication skills not previously required.

Some partners expressed difficulties understanding and responding to emotional needs. Issues of uncertainty, frustration and fear for the PwMS led to the expression of emotions or fluctuations of mood that the partner had not previously experienced. They struggled to determine from where the

emotions were coming, whether there were reasons related to the illness or related to another cause such as ageing or hormonal fluctuations:

> Well, [partner] has her ups and downs. She can have bouts of depression, not deep depression, but her mood would swing quite a lot. You put that down to MS, but it may be just change of age and all sorts of reasons. (P18, M)

At other times they felt they knew that everything was alright but they could understand the fear that arose for the person when they experienced minor problems, but that this had to be dealt with along with the other challenges of life:

> He sometimes wakes up and he's like, "oh this is the start of the end" and he gets quite dramatic. I find things like that sometimes just frustrating because I know that it's not, but I think that is just the nature of an illness that you [can't] control…So, it's just trying to deal with that whilst trying to live, as well as the challenges of managing a family, work etc. (P20, F)

Partners found that MS proved a challenge to the couple's communication skills, challenges not previously experienced. There was discussion of fears, worries and frustrations that had never arisen before. However, some identified that MS and the experiences from the workshop had provided an opportunity to improve their communication skills. They reflected on new experiences of openly discussing symptoms, worries and frustrations:

> He'd learnt a few techniques of how to communicate better…we've used quite a few of those techniques that he learned [at the workshop]. We found that really helpful just to talk about issues that are frustrating us…rather than having an argument about it. (P20, F)

For some the workshop offered the first opportunity they had experienced to speak openly of their feelings with each other, to find the time and space to have these discussions and to express things previously unexpressed:

> I think the other beneficial thing was…at the retreat I was asked to tell my partner how I felt about him… some quite personal questions that we had to sit and discuss, and we had never discussed things particularly at that level and to that depth. (P3, F)

Some couples had only begun their relationship following the diagnosis of MS, so the partner did not see the illness or coping with lifestyle modifications as any hurdle to their continuing relationship and connectedness:

> [Partner] had MS prior to she and I getting together, so it's always been there in our relationship… so, in terms of me adapting to [Partner] and MS, it came together really well. (P5, M)

3.2.3 | Togetherness

Togetherness was a strong positive theme. Most of the positivity arose from making decisions together regarding making life changes and working as a team with shared purpose.

The sense of togetherness from making decisions varied from practicalities of lifestyle modification to more major life decisions. For some partners who attended the workshop, even the shared decision to attend was an important shared decision:

> I think the really important thing was that we made the decision to go [to the workshop] as a couple - and we tend to do lots of things as a couple - because we were able to experience the whole thing together. (P3, F)

For others, shared decisions were made regarding change of career, workplace and country of residence, aimed at achieving their desired work-life balance and reducing stress of city living and overly busy employment, and a chance to live in a more nurturing environment.

Teamwork was identified as important in undertaking major lifestyle modifications. Some had exercised together for the first time or taken up sports together that only one had previously done, so attempts to improve physical fitness led to new joint experiences. Working hard together as a team was seen as a way to ensure the longevity of the relationship, whereas not working as a team could highlight weaknesses within the couple's relationship:

> We're probably a very good team as result of what we've done together. It was a real teamwork thing I think. It's very hard for someone to do [lifestyle modification] on their own. Very hard. If there's any cracks in the relationship, that will be the end of it. (P1, F)

Flowing from making significant decisions and changes together, partners described a greater sense of togetherness evolving between them and, for some, a secure sense of being together through any challenge:

> We do most things together. We don't work together, but when we have time together we are together as a couple. In terms of our future, that's just how it will be. Whatever happens to him in terms of how the disease might progress or not progress, we'll face that together basically. (P3, F)

For some participants, following from the practicalities of working and making decisions together came the sense of deepening of their

relationship and becoming closer. Some participants expressed that attending the workshop together had been an important milestone in their development of closeness:

> We were very close before anyway but [the workshop] brought us much closer together because now we share, just through the lifestyle things, we share way more things in common and do more things in common. (P4, F)

One participant described how MS and the lifestyle changes had challenged and strengthened them and affirmed their bond to the point where their future seemed certain:

> The lifestyle as much as anything, the changes…have benefited our relationship. It's definitely made us stronger because we both made the changes so we went through it together. [Partner] and I will be together forever. We've always said that if we can go through all the things that we've been through before we were married, [the future will] be a lot easier. (P7, F)

4 | DISCUSSION

Much of the literature regarding couples where one person has MS explores how couples cope with uncertainty regarding their future (Bogosian et al., 2009; Strickland et al., 2015), adapt and adjust to the illness and the changes it brings (Blank & Finlayson, 2007; Boland, Levack, Hudson, & Bell, 2012; Courts, Newton, & McNeal, 2005), and how partners transition to caring roles. The themes arising from these qualitative explorations therefore usually reflect uncertainty, adaptation and transition, and their impact on relationships. A thematic synthesis of qualitative studies of partners' transitions to caregiving roles confirmed such themes, identifying relationship changes of becoming closer while adapting to illness, working together to achieve goals, overcoming problems together and the challenges of changing roles, fluctuating emotions and feelings of loss (Killner & Soundy, 2018). The positive outcomes for couples in these analyses were, in general, positives arising from hardship and adjustment, as described previously (Pakenham, 2005a, 2005b).

Similarities were identified between some of our themes and those in the literature. For example, Boland and colleagues described similar results to our theme of providing support, reporting that couples supported each other with the struggles of day-to-day life by normalising life, sharing domestic responsibilities, finding positives and dealing with one day at a time (Boland et al., 2012). Similar to partners in our study, partners of people with other life altering illnesses identified that finding the balance of providing appropriate support and allowing independence was a feature of their relationships. Partners fluctuated between providing 'leaping in care' where the partner struggled with boundaries for providing care and used a dominating model of care, and 'leaping ahead care' when they sought to give back control, allowing the person with the illness to maintain independence (Gullick et al., 2017). These findings were similar to our study's theme where balancing providing support and handing back responsibility to encourage independence were also identified. However, many of our participants had a 'different take' on providing support and adopted proactive approaches and saw positives for themselves, the person, and the relationship. They witnessed the benefits of joining the person with MS in their attempts to adopt dietary modification, exercise and decrease stress, and saw many advantages for their relationship flowing from these supportive efforts.

In our second theme of remaining connected, our partners' attempts to understand and respond to emotional needs, and to manage challenging communication had similarities with other qualitative research. Courts found that spouses struggle to make sense of unclear symptoms or emotional fluctuations and try to provide support and continue normal routines (Courts et al., 2005). In this respect, our participants' experiences were very similar to those previously identified. Some in our study also felt their communication skills were inadequate and that challenges of communicating effectively were ongoing. However, others felt they had developed their communication skills and, having used strategies learned during the workshops, identified improved communication and openness in the relationship as a positive outcome. Previous studies have found that couples coping with chronic illness do best when they consistently communicate effectively, have open discussions and develop shared ideas regarding what gives them meaning and satisfaction with life (Busch, Spirig, & Schnepp, 2014). Other research found that couples dealing with chronic illness may find talking about the nature and state of their relationship a potentially useful tool and may benefit more than healthy couples from developing this skill (Badr & Acitelli, 2005). A systematic review of coping in couples with MS suggested beneficial effects of interventions to strengthen both partners in their communication skills to enhance relationship quality (Busch et al., 2014). These studies suggest that the improved communication skills developed by our participants from attendance at the workshop may, in part, have improved the quality of their relationship. Moreover, couples with higher relationship quality may be better able to cope with the stresses of MS (McPheters & Sandberg, 2010).

With respect to the theme of togetherness, others have identified that MS may result in feeling closer as a couple. Finding the positives that arise from challenges and the benefits that arise from adversity (Killner & Soundy, 2018; Pakenham, 2005a, 2005b), 'journeying together' (Boland et al., 2012), where couples described being 'intertwined' and 'part of a unit', suggest that couples feel closer for many reasons. Success at achieving things together has also been described, however, the successes described were often in adaptation to care-giving roles (Courts et al., 2005; Killner & Soundy, 2018). Our participants found greater closeness arose, not from adversity, but from proactively modifying their lifestyle together, making major decisions and working hard together. They reported achieving substantial goals relating to health, adjusting their

careers and lifestyle, and achieving their desired work-life balance. Such outcomes are rarely described in the literature, as our study is the first to examine the influence of adopting lifestyle modification on partners of PwMS.

Most research has explored the experiences of partners of PwMS who adopted standard medical management and many studies examined partners in care-giving roles. The participants in our study were partners of those who had attended a workshop for modification of lifestyle-related risk factors for MS, in conjunction with standard medical management. In our study, only five of our 21 participants' partners had a mobility limitation. Many of the PwMS were fit and well, participating in sometimes strenuous physical activities and were still working and undertaking many aspects of family life. Although nine partners were aged over 60, only six had retired and only one partner was unable to work while the person with MS continued to work. These characteristics indicate that most participants were partners of people without significant disability, although two of our retired participants were providing some care to the person with MS. The scope and abilities of PwMS and their partners in this study may therefore differ from others previously studied, although it should be noted that we did not assess forms of disability other than mobility or other significant MS symptoms. Therefore, these partners' reflections were not largely those of adjusting to disability or a caring role as part of their relationship. While there appears to be differences in our sample from previously described populations, the intention of this research was explicitly to explore the experiences of this particular group of partners.

Characteristics of those who declined participation are not known and their experiences may have differed from those presented. Those willing to participate may have been more highly motivated and had more positive experiences that they wished to share. All partners were in a current relationship and all relationships were heterosexual. Therefore, experiences of those who were separated or divorced and in non-heterosexual relationships were not explored.

While some participants felt that MS had provided little benefit to their relationship, others expressed positive outcomes that went beyond benefits arising from adversity. These included the opportunity to share new challenges such as diet and exercise, change their lives and careers in proactive ways, embark on opportunities to communicate better, and a genuine sense of closeness and togetherness that enhanced their relationship and QOL. The early adoption of a 'we' approach to coping with MS by patients and spouses starting from the time of initial diagnosis has been recommended as a way of enhancing outcomes for people with MS and their partners (Samios et al., 2015). Recommendations for the person with MS and their partner to adopt lifestyle modification early in the MS journey is consistent with this approach and may have implications for the person with MS, their partner and their intimate relationship, with realistic expectation of genuine positive outcomes. Future research exploring potential dual benefits of lifestyle change for couples affected by MS may help fill this important gap in the literature and provide realistic hope about their future, particularly for people newly diagnosed with MS.

5 | CONCLUSION

Our study of partners of PwMS undertaking significant lifestyle changes revealed a number of novel themes regarding their relationships. The shared experiences of partners in undertaking this journey together with the person with MS led many to report better communication, and a sense of becoming closer and more connected in their lives together.

ETHICS APPROVAL

The study was approved by the University of Melbourne Human Research Ethics Committee (ID number 1545280.1).

ACKNOWLEDGEMENTS

The authors thank the participants for their time and thoughtful reflections.

CONFLICT OF INTEREST

George Jelinek receives royalties for the book, Overcoming Multiple Sclerosis, which outlines the pillars of the residential lifestyle workshop. Sandra Neate, Keryn Taylor and George Jelinek have received remuneration for facilitating the workshops.

ORCID

Sandra L. Neate https://orcid.org/0000-0002-0761-9848
George A. Jelinek https://orcid.org/0000-0001-6157-0910
Steve Simpson, Jr https://orcid.org/0000-0001-6521-3056

REFERENCES

Ackroyd, K., Fortune, D. G., Price, S., Howell, S., Sharrack, B., & Isaac, C. L. (2011). Adversarial growth in patients with multiple sclerosis and their partners: Relationships with illness perceptions, disability and distress. *Journal of Clinical Psychology in Medical Settings*, *18*(4), 372–379. https://doi.org/10.1007/s10880-011-9265-0

Aronson, K. J. (1997). Quality of life among persons with multiple sclerosis and their caregivers. *Neurology*, *48*(1), 74–80. https://doi.org/10.1212/WNL.48.1.74

Badr, H., & Acitelli, L. K. (2005). Dyadic adjustment in chronic illness: Does relationship talk matter? *Journal of Family Psychology*, *19*(3), 465–469. https://doi.org/10.1037/0893-3200.19.3.465

Beck, C. T. (1993). Qualitative research: The evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research*, *15*(2), 263–266. https://doi.org/10.1177/019394599301500212

Blank, C. W., & Finlayson, M. (2007). Exploring the impact of multiple sclerosis on couples: A pilot study. *Canadian Journal of Occupational*

Therapy, *74*(2), 134–142. https://doi.org/10.1177/000841740707400201

Bogosian, A., Moss-Morris, R., Yardley, L., & Dennison, L. (2009). Experiences of partners of people in the early stages of multiple sclerosis. *Multiple Sclerosis Journal*, *15*(7), 876–884. https://doi.org/10.1177/1352458508100048

Boland, P., Levack, W. M., Hudson, S., & Bell, E. M. (2012). Coping with multiple sclerosis as a couple: 'peaks and troughs' - an interpretative phenomenological exploration. *Disability and Rehabilitation*, *34*(16), 1367–1375. https://doi.org/10.3109/09638288.2011.645115

Busch, A. K., Spirig, R., & Schnepp, W. (2014). Coping with multiple sclerosis in partnerships: A systematic review of the literature. *Nervenarzt*, *85*(6), 727–737. https://doi.org/10.1007/s00115-014-4017-7

Chruzander, C., Ytterberg, C., Gottberg, K., Einarsson, U., Widen Holmqvist, L., & Johansson, S. (2014). A 10-year follow-up of a population-based study of people with multiple sclerosis in Stockholm, Sweden: Changes in health-related quality of life and the value of different factors in predicting health-related quality of life. *Journal of the Neurological Sciences*, *339*(1–2), 57–63. https://doi.org/10.1016/j.jns.2014.01.020

Clancy, M. (2013). Is reflexivity the key to minimising problems of interpretation in phenomenological research? *Nurse Researcher*, *20*(6), 12–16. https://doi.org/10.7748/nr2013.07.20.6.12.e1209

Courts, N. F., Newton, A. N., & McNeal, L. J. (2005). Husbands and wives living with multiple sclerosis. *Journal of Neuroscience Nursing*, *37*(1), 20–27. https://doi.org/10.1097/01376517-200502000-00004

Crist, J. D., & Tanner, C. A. (2003). Interpretation/analysis methods in hermeneutic interpretive phenomenology. *Nursing Research*, *52*(3), 202–205. https://doi.org/10.1097/00006199-200305000-00011

D'Alisa, S., Miscio, G., Baudo, S., Simone, A., Tesio, L., & Mauro, A. (2006). Depression is the main determinant of quality of life in multiple sclerosis: A classification-regression (CART) study. *Disability and Rehabilitation*, *28*(5), 307–314. https://doi.org/10.1080/09638280500191753

D'hooghe, M. B., Nagels, G., Bissay, V., & De Keyser, J. (2010). Modifiable factors influencing relapses and disability in multiple sclerosis. *Multiple Sclerosis Journal*, *16*(7), 773–785. https://doi.org/10.1177/1352458510367721

Dibley, L., Williams, E., & Young, P. (2019). When family don't acknowledge: A hermeneutic study of experience of kinship stigma in community-dwelling people with inflammatory bowel disease. *Qualitative Health Research*, https://doi.org/10.1177/1049732319831795

Figved, N., Myhr, K. M., Larsen, J. P., & Aarsland, D. (2007). Caregiver burden in multiple sclerosis: The impact of neuropsychiatric symptoms. *Journal of Neurology, Neurosurgery and Psychiatry*, *78*(10), 1097–1102. https://doi.org/10.1136/jnnp.2006.104216

Fitzgerald, K. C., Tyry, T., Salter, A., Cofield, S. S., Cutter, G., Fox, R., & Marrie, R. A. (2018). Diet quality is associated with disability and symptom severity in multiple sclerosis. *Neurology*, *90*(1), e1–e11. https://doi.org/10.1212/WNL.0000000000004768

Gottberg, K., Chruzander, C., Einarsson, U., Fredrikson, S., Johansson, S., & Widen Holmqvist, L. (2014). Health-related quality of life in partners of persons with MS: A longitudinal 10-year perspective. *British Medical Journal Open*, *4*(12), e006097. https://doi.org/10.1136/bmjopen-2014-006097

Gullick, J., Krivograd, M., Taggart, S., Brazete, S., Panaretto, L., & Wu, J. (2017). A phenomenological construct of caring among spouses following acute coronary syndrome. *Medicine, Health Care and Philosophy*, *20*(3), 393–404. https://doi.org/10.1007/s11019-017-9759-0

Hadgkiss, E. J., Jelinek, G. A., Weiland, T. J., Pereira, N. G., Marck, C. H., & van der Meer, D. M. (2013). Methodology of an International Study of People with Multiple Sclerosis Recruited through Web 2.0 Platforms: Demographics, Lifestyle, and Disease Characteristics. *Neurology Research International*, *2013*, 1–12. https://doi.org/10.1155/2013/580596

Hadgkiss, E. J., Jelinek, G. A., Weiland, T. J., Rumbold, G., Mackinlay, C. A., Gutbrod, S., & Gawler, I. (2013). Health-related quality of life outcomes at 1 and 5 years after a residential retreat promoting lifestyle modification for people with multiple sclerosis. *Neurological Sciences*, *34*(2), 187–195. https://doi.org/10.1007/s10072-012-0982-4

Hakim, E. A., Bakheit, A. M. O., Bryant, T. N., Roberts, M. W. H., McIntosh-Michaelis, S. A., Spackman, A. J. ... McLellan, D. L. (2000). The social impact of multiple sclerosis–a study of 305 patients and their relatives. *Disability and Rehabilitation*, *22*(6), 288–293. https://doi.org/10.1080/096382800296755

Hammond, S. R., McLeod, J. G., Macaskill, P., & English, D. R. (1996). Multiple sclerosis in Australia: Socioeconomic factors. *Journal of Neurology, Neurosurgery and Psychiatry*, *61*(3), 311–313. https://doi.org/10.1136/jnnp.61.3.311

Hempel, S., Graham, G. D., Fu, N., Estrada, E., Chen, A. Y., Miake-Lye, I., ... Wallin, M. T. (2017). A systematic review of modifiable risk factors in the progression of multiple sclerosis. *Multiple Sclerosis Journal*, *23*(4), 525–533. https://doi.org/10.1177/1352458517690270

Horrigan-kelly, M., Millar, M., & Dowling, M. (2016). Understanding the Key Tenets of Heidegger's Philosophy for Interpretive Phenomenological Research. *The International Journal of Qualitative Methods*, *15*, 1–8. https://doi.org/10.1177/1609406916680634

Ironside, P. M. (2006). Using narrative pedagogy: Learning and practising interpretive thinking. *Journal of Advanced Nursing*, *55*(4), 478–486. https://doi.org/10.1111/j.1365-2648.2006.03938.x

Jelinek, G. A., De Livera, A. M., Marck, C. H., Brown, C. R., Neate, S. L., Taylor, K. L., & Weiland, T. J. (2016). Lifestyle, medication and sociodemographic determinants of mental and physical health-related quality of life in people with multiple sclerosis. *BMC Neurol*, *16*(1), 235. https://doi.org/10.1186/s12883-016-0763-4

Killner, L., & Soundy, A. (2018). Motivation and experiences of role transition in spousal caregivers of people with multiple sclerosis. *International Journal of Therapy and Rehabilitation*, *25*(8), 405–413. https://doi.org/10.12968/ijtr.2018.25.8.405

Levin, A. B., Hadgkiss, E. J., Weiland, T. J., Marck, C. H., van der Meer, D. M., Pereira, N. G., & Jelinek, G. A. (2014). Can meditation influence quality of life, depression, and disease outcome in multiple sclerosis? Findings from a large international web-based study. *Behavioural Neurology*, *2014*, 916519. https://doi.org/10.1155/2014/916519

Li, M. P., Jelinek, G. A., Weiland, T. J., Mackinlay, C. A., Dye, S., & Gawler, I. (2010). Effect of a residential retreat promoting lifestyle modifications on health-related quality of life in people with multiple sclerosis. *Quality in Primary Care*, *18*(6), 379–389.

Marck, C. H., De Livera, A. M., Brown, C. R., Neate, S. L., Taylor, K. L., Weiland, T. J., ... Jelinek, G. A. (2018). Health outcomes and adherence to a healthy lifestyle after a multimodal intervention in people with multiple sclerosis: Three year follow-up. *PLoS ONE*, *13*(5), e0197759. https://doi.org/10.1371/journal.pone.0197759

Marck, C. H., Hadgkiss, E., Weiland, T. J., van der Meer, D. M., Pereira, N., & Jelinek, G. A. (2014). Physical activity and associated levels of disability and quality of life in people with multiple sclerosis: A large international survey. *BMC Neurology*, *14*, 143. https://doi.org/10.1186/1471-2377-14-143

McCabe, M. P., & McDonald, E. (2007). Perceptions of relationship and sexual satisfaction among people with multiple sclerosis and their partners. *Sexuality and Disability*, *25*(4), 179–188. https://doi.org/10.1007/s11195-007-9053-9

McConnell-Henry, T., Chapman, Y., & Francis, K. (2011). Member checking and Heideggerian phenomenology: A redundant component. *Nurse Researcher*, *18*(2), 28–37. https://doi.org/10.7748/nr2011.01.18.2.28.c8282

McPheters, J. K., & Sandberg, J. G. (2010). The relationship among couple relationship quality, physical functioning, and depression in multiple sclerosis patients and partners. *Families, Systems, & Health*, *28*(1), 48–68. https://doi.org/10.1037/a0018818

Nowell, L. S., Norris, J. M., White, D., & Moules, N. J. (2017). Thematic analysis: Striving to meet trustworthiness criteria. *International Journal of Qualitative Methods*, *16*, 1–13. https://doi.org/10.1177/1609406917733847

Pakenham, K. I. (2005a). Benefit finding in multiple sclerosis and associations with positive and negative outcomes. *Health Psychology*, *24*(2), 123–132. https://doi.org/10.1037/0278-6133.24.2.123

Pakenham, K. I. (2005b). The positive impact of multiple sclerosis (MS) on carers: Associations between carer benefit finding and positive and negative adjustment domains. *Disability and Rehabilitation*, *27*(17), 985–997. https://doi.org/10.1080/09638280500052583

Pfleger, C. C., Flachs, E. M., & Koch-Henriksen, N. (2010). Social consequences of multiple sclerosis. Part 2. Divorce and separation: A historical prospective cohort study. *Mult Scler*, *16*(7), 878–882. https://doi.org/10.1177/1352458510370978

Samios, C., Pakenham, K. I., & O'Brien, J. (2015). A dyadic and longitudinal investigation of adjustment in couples coping with multiple sclerosis. *Annals of Behavioral Medicine*, *49*(1), 74–83. https://doi.org/10.1007/s12160-014-9633-8

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, *8*(3), 27–37. https://doi.org/10.1097/00012272-198604000-00005

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., … Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, *52*(4), 1893–1907. https://doi.org/10.1007/s11135-017-0574-8

Strickland, K., Worth, A., & Kennedy, C. (2015). The experiences of support persons of people newly diagnosed with multiple sclerosis: An interpretative phenomenological study. *Journal of Advanced Nursing*, *71*(12), 2811–2821. https://doi.org/10.1111/jan.12758

Thormann, A., Sorensen, P. S., Koch-Henriksen, N., Thygesen, L. C., Laursen, B., & Magyari, M. (2017). Chronic comorbidity in multiple sclerosis is associated with lower incomes and dissolved intimate relationships. *European Journal of Neurology*, *24*(6), 825–834. https://doi.org/10.1111/ene.13297

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

How to cite this article: Neate SL, Taylor KL, Jelinek GA, et al. On the path together: Experiences of partners of people with multiple sclerosis of the impact of lifestyle modification on their relationship. *Health Soc Care Community*. 2019;27:1515–1524. https://doi.org/10.1111/hsc.12822

Author/s:
Neate, SL; Taylor, KL; Jelinek, GA; De Livera, AM; Simpson, S; Bevens, W; Weiland, TJ

Title:
On the path together: Experiences of partners of people with multiple sclerosis of the impact of lifestyle modification on their relationship

Date:
2019-08-01

Citation:
Neate, SL; Taylor, KL; Jelinek, GA; De Livera, AM; Simpson, S; Bevens, W; Weiland, TJ, On the path together: Experiences of partners of people with multiple sclerosis of the impact of lifestyle modification on their relationship, HEALTH & SOCIAL CARE IN THE COMMUNITY, 2019, 27 (6), pp. 1515 - 1524

Persistent Link:
http://hdl.handle.net/11343/238691