“Just be Here”: Couples’ Experiences of Dyadic Coping in Multiple Sclerosis.

Background and Aims

Multiple Sclerosis (MS) is a disease that typically impacts both the person with MS and their romantic partner. It is well recognised that when MS affects one partner, both partners often take a role in managing illness together, as a “dyad”. However, there is relatively little research available on couples’ experiences of coping with MS. This research aimed to explore couples’ experiences of MS, to provide a better understanding of how couples cope with this disease together.

Methodology

As part of this research, we interviewed couples about their experiences of coping with MS. Couples were recruited through MS Ireland, MS Trust UK and MS- UK. In this study, we first interviewed couples together. Then, both partners were also offered a short, follow-on individual interview to provide any further comment. In the interviews, couples were asked about how MS has impacted their shared lives, how they have coped together, and how they thought about the future. Each interview was analysed in an in-depth way using a method named Interpretative Phenomenological Analysis. This analysis was used to gain in-depth insights into the couple’ s experiences as a dyad. We also looked for patterns of responses across all interviews.

The final sample for this research included 11 couples, who ranged in age from 31-58 years. The length of the couples’ relationships varied from 7-28 years. All participants were assigned pseudonyms, and all potentially identifying information was removed from the findings.

Findings

In general, couples spoke about how they coped with MS as a unit and how each partner influenced one another’s experience over time. It appeared that unclear communication around MS often led to a period of emotional distancing in the couple relationship. Yet, developing new ways to communicate around MS over time supported couples to become more aligned in their approach to managing MS together.

The following three themes were used to express the key findings from this study: a) “Interacting Individual and Dyadic Coping Experiences,” b) “Evolving Communication and Understanding,” and c) “Regaining Control through the Dyadic Experience. These themes are described in further detail below.

Theme 1: Interacting Individual and Dyadic Coping Experiences

The findings of this research suggest that each partner faces unique challenges in managing MS as either the person living with MS, or the partner of someone living with MS. In many cases, each partner had different ways of coping with the disease. Some couples felt that their unique personalities, backgrounds and life experiences led to the differences in how each partner coped with MS. At times, having different approaches to managing MS challenged the couple's relationship, and led to tension or disagreement between partners. Yet, other couples spoke about how their differences were helpful for providing balance in their different perspectives on managing MS, as told by one couple:

> *Kate (person with MS): "He does put things into perspective… It's easy to overthink and read too much. So, you do need reminding… it definitely does help."*
>
> *Tim (partner): "…I try to put it in perspective what she's thinking… Rather than overwhelming herself with what could happen or what will happen, which we don't know. So, it is always trying to bring her back to the present."*

Some couples spoke about intentionally trying to hide their distress around the MS from their partner in order to protect themselves or each other. Yet, concealing their true emotions often led to one partner misinterpreting the other's needs and difficulties. From the perspective of many people with MS, their partners' attempts to fix or provide solutions to the problem of MS were sometimes perceived as unhelpful. Often the person with MS simply sought their partner's emotional presence, highlighted in the quote below:

> *Anonymous quote from individual interview (person with MS):*
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> *"… my partner does try to be solution-focused and sometimes it's kind of… you can't always be solution focused, we, we can't change what this is… Stop trying to find solutions to this problem right now and just sit down and just be here… you know you can't make this go away."*

Theme 2: Evolving communication and understanding

In this research, couples often spoke about their process of developing new ways to communicate around MS. Having some form of open communication allowed couples to better understand one another's' difficulties around MS and provide the right type of support to one another. Most couples felt that their communication has become increasingly open since the MS diagnosis. For example, one couple discussed using more formal check-ins to gain a deeper understanding of their partner's needs:

> *Susan (person with MS): "We also do check-ins. We do talk frequently about our needs…. We both wrote a list of ways that we want the other to love us. And that was because it was something we were missing. So, we kind of check what is or isn't happening at the moment, why is it or is it not happening…"*

> *Danielle (partner): “What's feeling good, what's not feeling good.”*
>
> *Susan (person with MS): “Yeah, what unmet needs are there. What expectations are reasonable and unreasonable.”*

Yet, couples described this shift in their communication as a continuous process that changed as the disease progressed. Despite the approach used, communicating their needs and experiences helped each partner to better understand the other’s inner experience. In this way, each partner felt more able to respond more sensitively to their partner’s needs.

Theme 3: Regaining control through the dyadic experience

Many couples spoke about the uncertainty they faced when living with MS, which made MS different to other diseases. Yet, having a strong and trusting partnership provided a sense of safety for couples coping with the continuous loss and change that often comes with MS. Several of the couples in this research focused on proactively taking steps to cope with MS through their joint efforts (i.e. changing to a healthier diet, regularly exercising together, use of supplements, attending therapies, researching MS online). Taking action together allowed couples to regain a sense of control with MS, exemplified by one couple in the following extract:

> *Camila (partner): “The thing is, we kind of agree in the way of seeing it... it's better to be proactive in approach and I think we both agree on that sense. So for example, when we talked about medication it was like, OK, let's see what's the best medication for you.”*
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> *Frank (person with MS): “...I think what's useful for me is now that Camila is fully on board. It's really useful in terms of... If I see something about MS, you know might be a new medication, might be a new trial, might be something from a neurologist, she's more interested to look at it and process it and give me her opinion and all that which is really, really helpful.”*

Finally, couples spoke of re-assessing their life values in the face of MS and making adjustments to their lives. Many of these couples described the benefits that came from their shared experience of MS, such as personal development, increased empathy or gratitude, which was highlighted by one couple in the following extract:

> *Karen (partner): “...the gift that MS gave us is that it helped us... So, as you get older, you realize that life is precious, and life is short. But we were confronted with that stark reality at a much earlier age than you might normally be, and rather than being despairing at it, we were like, well, we’re gonna squeeze every little bit out of what we can.”*
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> *Joe (person with MS): “... And I think, yeah, it’s, it’s, you know, don’t, don’t waste your energy worrying about it [MS].”*

Our conclusions

Overall, the findings of this research suggest that many couples consider MS to be a shared experience. The findings also recognise the medical, emotional and lifestyle uncertainty that often comes with MS.

In general, it appeared that individual differences contributed to differences in how each partner coped with MS. For some couples, their differences led to tension or disagreement. Yet, many others found these differences as helpful for providing a balanced perspective on the disease. For many couples, developing more open communication over time allowed partners to become more sensitive towards one another's needs related to the disease. In addition, having a secure and trusting partner relationship provided a sense of safety or comfort when coping with MS. Despite the adversity that couples faced, all the couples in this research appeared to experience some level of growth, as individuals, and as a couple, as a result of their joint MS experience.

The findings of this study would suggest that professionals should consider MS as a shared experience for couples. For couples living with MS, they may wish to explore a range of different communication strategies that might meet their unique needs. For example, this may include direct, open verbal communication or written communication. Couples may have different communication needs at different stages of the disease. The findings also show that there is a need for further research exploring couples' experiences of coping with MS, from the perspective of both partners.

Key conclusions

- Individual differences between partners may lead to differences in how each partner copes with an MS diagnosis. Some couples may find these differences helpful for providing an alternative perspective to their own. For other couples, their differences may cause tension in their relationship.
- Developing clear communication around MS may support couples to become more sensitive to each others' needs around MS.
- Collaboration in their coping, or taking action together, may allow couples to gain a sense of control over MS.
- As MS comes with a lot of uncertainty, it may lead couples to re-assess their life values.

Publication of the research

The published study in its entirely may be accessed at https://journals.sagepub.com/doi/full/10.1177/02654075241309381

This research will also be presented at the Psychological Society of Ireland Annual Conference in November 2025. Full conference details can be found at The Psychological Society of Ireland (PSI)

Acknowledgements
A special thanks to all of the couples who took part in this study, and provided important perspectives on living with MS. Your participation in sharing your stories has been invaluable in this research.

Thank you to all of the staff at MS Ireland, MS UK and Ms Trust for supporting this project.

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