

# Identifying the Unmet Needs of Adults with Multiple Sclerosis (MS) Experiencing Cognitive Difficulties and Their Support Partners

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## INTRODUCTION

- Cognitive difficulties are a prominent but often overlooked feature in people with MS<sup>1</sup> and can be challenging for them and their families.<sup>2</sup>
- These difficulties impact the person with MS in areas such as employment<sup>3</sup>, health decisions<sup>4</sup>, decisions about risk<sup>5</sup>, managing money<sup>6</sup>, daily life tasks<sup>7</sup>, driving<sup>8</sup>, and interpersonal relationships.<sup>9</sup>
- These difficulties can impact the caregiver in areas such as increased informal care time<sup>10</sup>, depression<sup>11</sup>, reduced quality of life<sup>12</sup>, reduced employment<sup>13</sup>, and increased subjective burden.<sup>10</sup>
- It is important to learn more about how cognitive difficulties might impact the daily lives of people with MS and their support partners.

## AIM

- To identify the needs of adults with MS-related cognitive changes, and the needs of their support partners, and to use this information to inform an intervention that will address these needs, and improve the overall well-being of adults with MS and their support partners.

“Yeah, I had to stop working because of the MS... I love my job, but I had to stop doing it... and that-that was a big problem... when we first came up with the decision that I should stop working, I was not really happy.”

“Because I am – I was – I am a very organized person.”

“The thing is, my memory is such that I forget what I’m reading about. I read the same paragraph 3 times and I don’t remember what I read.”

“I used to be very good with math, simple mathematics, making estimates. I’m not good at that anymore, I don’t trust myself any longer.”

“I’m ready to work but I’m timid, you know, I’m very unsure about whether... because, things like fatigue and my memory are very frightening to me. How am I gonna hide those symptoms, you know, how am I going to hide those, those problems? Yeah, so that’s what I’m facing now.”

## METHODS

- 15 adults with MS, aged between 38 and 73 years ( $M = 60.2$ ) who reported difficulties with cognition and their spouses, aged between 44 and 73 years ( $M = 62$ ) were recruited through the NARCOMS\* registry and participated in separate semi-structured interviews. Adults with MS were 12 females and 3 males. The average number of years together was 30 years.
- The interviews sought information related to challenges faced by people with MS-related cognitive difficulties and their support partners. Topics included the impact of cognitive difficulties on each person, on their relationship, and on family relationships; and ideal, acceptable outcomes for an intervention targeting these challenges.
- A constant comparative method<sup>14</sup> was used to identify and code categories, while also comparing data to the wider literature.<sup>15</sup>

## RESULTS

- Couples identified how their shared experience brought them closer, and taught them how to empathize and support each other.
- Couples showed resilience dealing with daily issues by adapting to cognitive changes like ‘brain fog’, loss of focus or short term memory.
- Couples said they were impacted daily and found it difficult to discuss their needs and anxieties about cognitive changes, how to best help each other, and how to deal with feelings of impatience and guilt.
- Almost all participants said they would benefit from a program to teach them more about the impact of cognitive difficulties, and how to cope more effectively as a couple.

If you’d like to learn more, visit <https://www.myhealios.com/research> or get in touch via [info@myhealios.com](mailto:info@myhealios.com).

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## CONCLUSIONS

- Couples were interested in learning about cognitive changes in MS and how to manage changes now and in the future. Couples were interested in learning skills for daily management, strategies for reducing anxiety, tips for effective communication, problem solving and finding information about cognitive changes in MS. We will use these results to inform a resilience building program for people with MS and their support partners, which we will pilot this year.

“She knows when it’s the wrong word. Like last night, she made pesto last night and we were going to do it with linguine, then she said ‘pasghetti’ then she looked and started to laugh.”

“I guess the real frustrating thing for me... When food is on sale she is buying three of everything, then next week she forgets and buys more, there are certain things I do to compensate for what she does... I’ve got two stand up freezers running in my garage... no, seriously!”

“I think the biggest challenge is learning to have patience, you know, tasks take longer, things that you’re doing together take longer”

“I mean, I love my wife. How bad it gets, it doesn’t make a difference.”

“I don’t make a lot of friends, because I don’t relate to a whole lot of other men.”

“People just think that she can always, she can still do what she always did, and I don’t know if people notice the cognitive changes either because she’s, I mean, she’s very intelligent and she’s always been able to speak very well.”