


RESEARCH REPORT

Managing communication changes in persons with multiple sclerosis: Findings from qualitative focus groups

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Abstract

Background: There is growing recognition that communication can be affected in multiple sclerosis (MS) and can negatively impact relationships, employment and psychological well-being. Some persons with MS (PwMS) implement strategies to facilitate their communication; however, some do not. Most PwMS who report communication changes do not engage with speech–language pathology (SLP) services. This raises concerns that a large portion of communication changes associated with MS go under-recognized and unmanaged. Little is known about what PwMS want and need to facilitate effective communication.

Aim: To explore what PwMS want and need to better manage their communication changes.

Methods & Procedures: Three focus groups were conducted online using Zoom, with a total of 12 PwMS. Participants were an opportunistic sample of PwMS within Australia recruited via advertisements distributed to various MS organizations and clinics. Data were transcribed verbatim and analysed using thematic content analysis to provide a qualitative analysis of the data.

Outcomes & Results: Two main themes emerged: (1) accessible knowledge and a holistic approach; and (2) partnerships. Specifically, the identified wants and needs of participants included: (1) assessment; (2) information; (3) raising awareness; (4) support groups; (5) a whole-person approach to intervention; (6) geographically and economically accessible and navigable services; (7) effective patient–physician interactions; and (8) a multidisciplinary team-based approach (e.g., SLP, psychology, neuropsychology, occupational therapy).

Conclusions & Implications: This study identified a wide range of unmet wants and needs of PwMS related to communication changes. Participants wanted improved collaborative partnerships with healthcare professionals to better manage their communication changes. For example, healthcare professionals could ask PwMS about potential communication changes, provide education and

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make appropriate referrals. Education and information provision could focus on communication changes in MS, factors that trigger or exacerbate communication changes, impacts, self-management strategies, and available supports and services. Specific implications for clinical practice and future research are suggested in this paper, including ideas for patient education materials and content, suggestions for communication-specific screening and information that could be shared in patient–physician interactions, the development of guidelines to systematically screen, assess, manage and monitor communication changes in MS, and the design of evidence-based communication interventions for this clinical population. The results from this study can be used to guide the design of supports and services to help PwMS better manage communication changes, with the aim to reduce the negative impacts.

KEYWORDS

communication changes, focus groups, management, multiple sclerosis, patient perspective, qualitative

What this paper adds

What is already known on this subject

PwMS can experience communication changes across a range of domains, including speech, voice, fluency, expressive and receptive language, and cognitive–linguistic functions. These changes can have profound and far-reaching negative impacts on educational and vocational outcomes, social participation, relationships, psychological well-being, and quality of life. Most PwMS who report communication changes do not engage with SLP services. There has been little research exploring what PwMS want and need to help manage their communication changes.

What this paper adds to the existing knowledge

This research is the first study of its kind that sets out specifically to explore what PwMS want and need to better manage their communication changes. This study increases our understanding of, and provides valuable insights into, the specific types of supports and services PwMS desire to access, and the partnerships and kinds of interactions PwMS dream of having with healthcare professionals to manage these changes. This information can facilitate the development of future interventions to manage communication changes in MS.

What are the potential or actual clinical implications of this work?

PwMS wanted healthcare professionals to ask about potential communication changes, provide education and make appropriate referrals. When providing education and information on communication changes in MS, healthcare professionals should focus on covering symptoms, triggers, impacts, self-management strategies, and available supports and services. There is a timely need to develop guidelines and interventions to manage communication changes in MS to reduce their negative impacts.

INTRODUCTION

Multiple sclerosis (MS) is a chronic neurological condition with an estimated global prevalence of 2.8 million people (The Multiple Sclerosis International Federation Atlas of MS, 2020). Most persons with MS (PwMS) are diagnosed between the ages of 20 and 40 years, and prevalence studies point to a higher preponderance in females than males, with a 3:1 ratio (Harbo et al., 2013). The neuropathophysiology of MS is characterized by inflammation, demyelination and neuronal loss within the central nervous system (CNS) (Lassmann, 2004). The clinical course of MS can follow different patterns (also called subtypes or phenotypes), including relapsing-remitting, secondary progressive, progressive-relapsing and primary progressive (Lublin et al., 2014; Tafti et al., 2021). These MS subtypes are determined by disease activity and disease progression (Lublin et al., 2014). The disease process results in impaired transmission of electrical impulses to and from the CNS, resulting in a range of symptoms (Lassmann, 2004). The symptom profile of MS is markedly heterogeneous depending on the location of inflammation, demyelination and scarring (Lassmann, 2004). Common MS symptoms include vision problems, impaired bladder and bowel control, fatigue, tingling and numbness, gait disturbances, and weakness (Tullman, 2013).

PwMS can also experience communication changes. These changes can occur across a range of domains, including speech, voice, fluency, expressive and receptive language, and cognitive-linguistic functions (Arnott et al., 1997; Arrondo et al., 2010; Carotenuto et al., 2018; El-Wahsh et al., 2021a; Grossman et al., 1995; Noffs et al., 2018; Sofologi et al., 2020). Functionally, these impact on conversational ability, understanding spoken information and following conversations, difficulty interpreting figurative language, slower reading, spelling errors, and slower unclear speech with strained voice quality (Arnott et al., 1997; Arrondo et al., 2010; Carotenuto et al., 2018; El-Wahsh et al., 2021a; Grossman et al., 1995; Noffs et al., 2018; Sofologi et al., 2020). PwMS have reported that these communication changes can result in difficulty completing work tasks, loss of confidence, loneliness, embarrassment and frustration, with far-reaching consequences for their educational and vocational outcomes, social participation, relationships, psychological well-being and quality of life (El-Wahsh et al., 2021a; Klugman & Ross, 2002; Yorkston et al., 2001). Qualitative studies have shown that some PwMS also avoid communication and experience lowered self-esteem (El-Wahsh et al., 2021a; Klugman & Ross, 2002). While some PwMS employ

strategies to facilitate their communication, including compensatory strategies (e.g., circumlocution), practising before speaking, alternative communication (e.g., gesturing), and self-advocacy (Blaney & Lowe-Strong, 2009; El-Wahsh et al., 2021a), others do not (El-Wahsh et al., 2021a).

Notably, PwMS appear to have limited engagement with speech-language pathology (SLP) services (El-Wahsh et al., 2018, 2021a; Johansson et al., 2020; Klugman & Ross, 2002). This is concerning, as growing evidence shows that behavioural intervention can improve or sustain function for longer in other slowly progressive neurological conditions (El-Wahsh et al., 2021b; Jokel et al., 2014; Smith et al., 2011; Yuan et al., 2020). Accordingly, there is a need to identify barriers and facilitators perceived and experienced by PwMS in accessing supports and services, and to understand what PwMS want and need to better manage their communication changes.

Over the past decades, there has been a shift from the biomedical model of medicine to the holistic and multi-dimensional World Health Organisation's (WHO) International Classification of Functioning, Disability, and Health framework (ICF) (World Health Organization International Classification of Functioning, 2001). This shift has led to a renegotiation of the relationship between healthcare professionals and service users with more collaborative and mutual partnerships between patients and professionals, and recognition of 'the patient as expert' in the management of their healthcare needs (Singer et al., 2011). This collaborative approach emphasizes that the development of healthcare support and services should be informed by the patients/consumers to maximize relevance and promote engagement (Singer et al., 2011). To date, no research has investigated the wants and needs of PwMS to facilitate effective communication. The purpose of the current study was to address this gap by exploring what PwMS want and need to better manage their communication changes.

METHODS

This study used a qualitative focus group methodology with thematic content analysis to gain insights from PwMS to inform a consumer-driven solution. Ethical approval for this study was received through The University of Sydney Human Research Ethics Committee (reference number 2020/756) and complied with the Declaration of Helsinki ethical principles (World Medical Association Declaration of (Falter et al., 2022) Helsinki, 2001). All participants provided written informed consent prior to participation.



Participant recruitment

Opportunistic sampling was used to recruit sufficient numbers of participants. Participants were recruited from across Australia via advertisements placed with MS support groups, neurology clinics, the MS Australia website and social media platforms. To be eligible to participate, participants were required: (1) to speak English, (2) be ≥ 18 years of age, (3) to report a formal diagnosis of MS, (4) to report no coexisting neurological conditions/history, and (5) to report communication difficulties associated with MS.

Data collection

Data were collected through focus groups. Focus groups are well suited to capture a wide range of opinions, ideas, perspectives, experiences and attitudes about a topic within a relatively short period of time (Doody et al., 2013). Further, the dynamic nature of focus groups can help to produce insights and data that would be less accessible without such interaction (Doody et al., 2013; Krueger & Casey, 2014). All focus groups were conducted online using the Zoom audiovisual videoconferencing software. Several measures were used on the Zoom platform for security, including a waiting room, a meeting password, and instructions were given to participants to download and use the latest version of Zoom for increased encryption (Falter et al., 2022). Prior to releasing a participant from the waiting room, the researcher edited their screen name to display first name only. The focus groups were video-recorded using the Zoom record function and stored directly onto the university's secure cloud-based server. This online interface facilitated a wide geographical sampling across Australia despite the Covid-19 global pandemic, and removed barriers of cost, time and mobility associated with travel. Moreover, online focus groups have been found to yield similar outcomes to face-to-face focus groups (Flynn et al., 2018).

A total of 19 PwMS expressed interest in the study by emailing the research team in response to the advertisement. A member of the research team responded to potential participants with an information package containing the participant information statement and consent form. If there was no response 2 weeks after sending the information package, a follow-up email was sent. A total of 13 consent forms were returned. In total, three focus groups were carried out and each group contained four PwMS (i.e., a total of 12 participants). One PwMS did not participate in the focus group as they were unavailable during the data collection period. Code saturation was achieved

by the third group whereby no additional ideas emerged (Hennink et al., 2019), hence recruitment was then closed (refer to *data analysis* for more information on analyses and data saturation).

Prior to the group, participants completed an online survey. This survey collected background demographic (e.g., age) and clinical (e.g., MS subtype) information, and type of healthcare services accessed to manage MS symptoms (e.g., physiotherapy). Groups were organized based on the availability of participants. Each group met on one occasion for 90 min. No participants had a support person attend with them. The first author (S.E.) acted as moderator and the last author (K.B.) acted as facilitator for all groups. S.E. and K.B. were present at all focus groups, and are both certified practising speech–language pathologists experienced in working with individuals with acquired neurological communication disorders. The moderator directed the discussion and kept the conversation flowing. The facilitator made the recordings, took notes, summarized the discussion and asked additional clarifying questions. At the introduction of each focus group, the moderator made a statement on the importance of discussion and hearing from all participants (Krueger & Casey, 2014). All participants shared their experiences and the moderator frequently asked group members if they wished to add any further comments to the discussion threads of other members. Participants were provided with the opportunity to provide written feedback following their participation in the study. Four participants, with at least one from each group, responded and commented on how everyone had had a chance to speak, how the group was well facilitated and how they were provided with frequent summaries. At the end of each focus group, the facilitator presented a verbal summary of key points for verification by participants. After each focus group, S.E. and K.B. met to discuss the collected data and emergent themes. Audit trails were kept at every step of the data analysis process to describe the research and decision-making process. Specifically, the audit trails included examples of the coding process, descriptions of how themes and subthemes were developed from codes, and rationales for grouping codes together to form themes and subthemes.

An interview guide was informed by past research and discussion amongst the research team (see Table 1 in the additional supporting information). The interview centred around three core ideas about managing communication changes: *discovery* (past experiences), *dream* (ideals) and *design* (specific features). The same key questions were used across all groups, and the moderator used standardized prompts during the discussion to penetrate further and to seek clarification for example, 'tell us more'. The guide facilitated in-depth discussion whilst allowing

flexibility and freedom to elaborate and discuss unexpected issues important to the participants (Braun & Clarke, 2013).

Data analysis

Three researchers were directly involved in the transcription and analysis of the data (S.E., K.B. and S.B.). Participants names were de-identified with the participants represented with a pseudonym to ensure confidentiality. The focus groups were transcribed verbatim by S.E. and checked for accuracy by K.B. The transcripts were analysed using Braun and Clarke's six phases of thematic analysis for qualitative analysis of the transcripts (Braun & Clarke, 2006). Phases 1–3 were completed by S.E. after each focus group following discussion between the group facilitator and moderator. Phase 1 involved data familiarization and immersion, whereby the transcript and field notes were read by S.E. and initial ideas/patterns were noted. Phase 2 involved generating initial codes. In Phase 3, the list of codes was collated and sorted. Related codes were grouped and collapsed to form overarching themes and subthemes (see Table 2 in the additional supporting information for worked examples of the content analysis). Throughout each phase, S.E. and K.B. had repeated discussions and examined audit trails of analysis steps with the aim to maximize credibility and accountability (Patton, 1999). In phase 4, K.B. and S.B. reviewed the codes, themes and subthemes from the full dataset to ensure they were appropriate and captured all aspects of the data. Any discrepancies were solved through discussion until consensus was achieved. At this stage, it was confirmed code saturation had been reached, whereby no new or relevant data emerged. The rule of thumb proposed by Krueger and Casey (2014) is to plan three focus groups and analyse for patterns and themes across groups and to then determine if saturation has been reached. Hennink et al. (2019) discuss two approaches to data saturation: code saturation (the point in data collection when no additional issues are identified) and meaning saturation (the point at which we fully understand the issues identified and when no further insights or nuances are found). The aim of this preliminary study was to gain a better understanding of the general wants and needs of PwMS, and therefore code saturation was considered appropriate. Phase 5 involved further refining and finalizing of the themes, subthemes and exemplars. A summary of the final analysis of the full dataset was emailed to all participants for member-checking. Six participants (50%) responded and were satisfied with the analysis, and no further modifications were made. Phase 6 involved reporting on the results, as below.

RESULTS

Participant characteristics

A total of 11 females and one male participated, with an average age of 51.7 years (range = 25–66 years). All participants reported having relapsing-remitting MS. The average age that participants received their MS diagnosis was 39.4 years (range = 20–62 years), and participants had been living with MS for an average of 12.3 years (range = 2–38 years). Participants resided across four states in Australia. Over half the sample (66.7%) reported being currently employed in either a full or part-time capacity. The remainder of participants were retired due to disability (33.3%). Four participants (33.3%) reported accessing SLP services. See Table 3 in the additional supporting information for full details of participant characteristics.

Themes

Two major themes and eight subthemes emerged from the data (Figure 1). The first theme identified the types of supports and services PwMS wanted to better manage their communication changes. These included supports and services that were designed to be informative, comprehensive, whole-person focused, routine, empowering, affordable and easy to access. Theme two identified the partnerships and kinds of interactions PwMS dreamed of having with healthcare professionals to better manage their communication changes.

Direct quotations from participants are used to illustrate how themes and subthemes were derived and to reflect in their own words the wants and needs of PwMS. These quotations are participant generated and are reported in their true form (i.e., they have not been edited for grammar) and include errors, which may illustrate the communication changes the participants' experience. In the following quotations, an ellipsis /.../ is used to indicate an intentional omission of a word, sentence or section from a quotation without altering its meaning.

Theme 1: Accessible knowledge and a holistic approach

Subtheme 1.1: Assessment

All participants wanted regular evaluation and monitoring of their communication. Participants acknowledged that their physical skills were routinely evaluated during medical consults; however, this was not the case for their

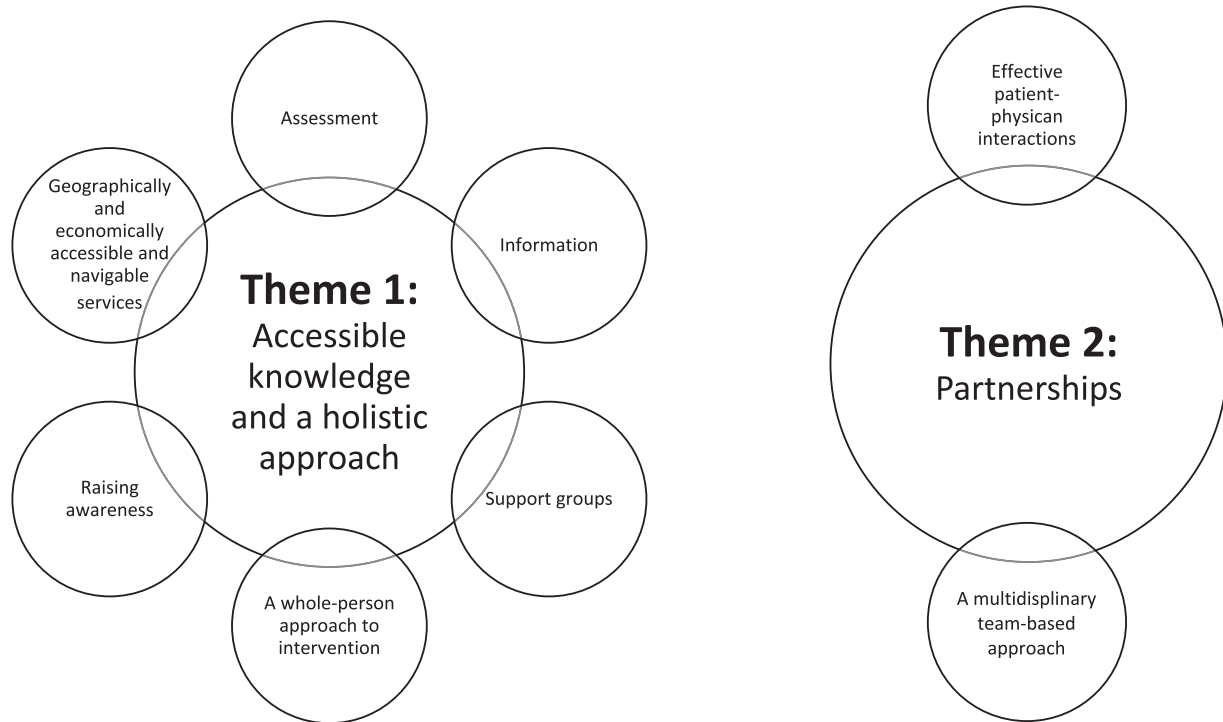


FIGURE 1 Summary of the themes and subthemes

communication. Participants wanted comprehensive MS care to routinely evaluate both physical and invisible symptoms, including communication.

Anna: General neurophysio assessments that we're used to ... muscle strength, reaction, coordination of hands like putting the little peg into (laugh) ... walking, getting in and out of your chair. It's all physical. I think the cognitive stuff and the physical usually are separate and maybe they need to have a bit more cognitive.

Betty: Whatever is put in place must be monitored, otherwise what's the point ... maybe we should every, I don't know, every 3, 4, 5 years have a cognitive assessment done ... so you can see whether things are you know stable or not ... which might alleviate some concern or stress that you have that it's actually erroneous ... and most people who are your age are experiencing these similar things.

One participant recounted a negative experience of having a communication assessment. She felt it was not beneficial because the tools that were used to evaluate her communication were not sensitive enough

to capture the difficulties she experienced in everyday activities.

Daisy: It seemed to me like the test was designed for someone of 70 with dementia, because it seemed very basic. And I came through with flying colours. ... She said, 'well, according to our tests you're fine, but obviously it's affected you'. ... They can show me a picture. ... But it's not the same as trying to work in everyday life.

On the other hand, several other participants recalled positive and valuable experiences with assessment, helping identify areas of strength and weaknesses and guide self-management.

Emma: She did quite an extensive three-hour exam on my cognition and sort of really worked out which parts of my cognition needed work on, and yeah word searching. ... She understood I was very stressed all the time, and she said, 'put your mobile phone on do not disturb so that you can answer the phone when you're ready and you've got it all together, so you're not you know, on the spot, trying to think something out' ... they were just great sort of tools.

Subtheme 1.2: Information

Most participants were frustrated that they did not receive information about communication changes associated with MS from their doctors. They wanted in-depth and easily accessible information about potential communication changes and practical self-management strategies (e.g., ways to find the right word to say).

Emma: Even though I've had it for 20 years, I didn't even know that there was cognitive issues with MS. I just bought it up [with my doctor] because I was really frustrated. ... Like, 'what's going on with me? ... why am I getting everything upside down ... saying the wrong things?' ... I didn't know there was an issue until I googled it.

Betty: They might mention it [cognitive issues], but that's just it ... practical suggestions are really good. It would be great if there were those and more like those somewhere accessible.

Further, participants also wanted educational material for their key communication partners (e.g., friends, spouses, carers, family) about communication changes associated with MS and how they can implement supportive strategies. Participants felt that such information would support their friends and family to manage their own frustration and learn practical ways to facilitate effective communication.

Felicity: An information pack maybe for carers or family ... examples of what communication difficulties are ... if they're able to identify them they are able to then I suppose help better.

Grace: I know that my husband wants to help me, but he doesn't know how to help ... if we had a cane or a walker, they know how to help us by opening doors or whatever, but they don't know how to help us when we have a cognitive problem. Ways of helping them know how to help us.

Participants noted that the timing of education was important. Most participants said that information about communication changes would have been beneficial at the time of diagnosis. They also wanted information to be eas-

ily accessible at any time over the longer term of the disease.

Daisy: I guess more information at the time of diagnosis and follow-up information.

Felicity: I was told not much at all about the communication aspects ... maybe the material that is designed to assist the newly diagnosed can focus a bit more on communication difficulties ... the material that I did read emphasized the point that cognitive issues or communication difficulties tend to present later ... but that is not the case ... maybe they shouldn't rule anything out.

Participants wanted recent and regularly updated educational materials to be available in a variety of different modalities. This included websites, videos, visual information, self-paced online programs, and both hard and soft copy resources.

Grace: A website designed just for the cognitive issues and have more detail in it than just say cognitive issues.

Kate: Little YouTube videos. Things that are around for people to follow about you know how to help themselves that would be of great value.

Emma: Infomercial illustrations ... education sort of things with a picture that sort of clearly says what's going on and then words to go with it.

Isobel: Program that we could go on to and just gain some skills ... different things that could be put in a little kit ... online or something to support us because that way, we could do it in our own time.

Subtheme 1.3: Support groups

Common to all participants was wanting to connect with other PwMS who experienced communication changes via support groups. Participants described a variety of potential positive outcomes of such groups, including validation, feeling less lonely and isolated, enjoyment,

gaining a sense of empowerment and hope, receiving emotional and non-judgemental support, and learning self-management strategies from each other.

Grace: You need support groups for the type of symptom you have ... it's like, 'thank God there's other people out there that are like me'. It's like finding your tribe.

Isobel: I like Charlie's idea of like a Zoom group speech pathology because going through any kind of change in symptoms or relapse it's very mentally exhausting because it's very alone ... that kind of shared experience would be so less, that feeling of loneliness ... and I'm sure so many people there'd be able to have different tools and the speech pathologist could find different ways to explain how to get something out.

Participants outlined ideas for the formation of such support groups, including the content and structure of the group. They wanted discussion on communication symptoms and practical self-management strategies specific to MS to facilitate effective communication. One participant suggested inviting guest speakers who could share evidence-based information on the topic. Most participants showed preference for an online format and discussed their increased confidence with virtual meetings and the surge of videoconferencing in the context of the Covid-19 pandemic. Other benefits included no travel time, overcoming physical barriers, and being in the comfort of their own home. A group facilitator was also suggested as helpful to manage the group and to guide the discussion, and two participants suggested this person could be a speech-language pathologist. It was also recommended that a loose meeting agenda be provided prior to the group to help members come prepared. All participants agreed on a monthly frequency. Some participants preferred evening meetings after work whilst others preferred during the day when they are less fatigued.

Grace: After last year [Covid-19], we've all learnt how to use Zoom. ... Could have a loose agenda of what topics you want to speak about. And then people will be prepared. Our problem is that it's hard to think off the top of our head.

Charlie: A forum to share those strategies. Your (Kate) thing of being calm, taking more

time to think before things happen ... having sort of a forum like this would be very helpful place to be with the speech pathologist.

Subtheme 1.4: A whole-person approach to intervention

Several participants acknowledged that communication effectiveness and participation can be affected by a variety of factors such as stress, frustration, fatigue and confidence. Accordingly, they wanted other factors to be considered in management of communication changes, such as fatigue management, confidence-building, and emotional and psychological support to manage the impacts.

Kate: You know mindfulness training and things like that. ... It's about staying calm because it's infuriating ... it's one of the most frustrating things. You just want to say banana, but you keep on saying apple. ... So, there's a level of psychology.

Anna: I think along with mindfulness, almost like a level of confidence as a way of coping, so we don't always have to feel we need to submit to this socio-cultural expectation of speech. ... It's very hard sometimes facing the world and you have all these invisible things ... and all these expectations. And communication is a huge one. Confidence and mindfulness as part of that kind of group would be really helpful. So, another tool, besides how to speak well.

Subtheme 1.5: Raising awareness

Participants relayed a range of misconceptions that the public have about MS and invisible symptoms. They described people associating MS with physical disabilities and wheelchairs. Common to all participants was the wish to raise awareness of the invisible MS symptoms, including communication changes, amongst the public to help eliminate misconceptions and to help the public learn ways to better support PwMS.

Lily: A lot of people just don't know. ... From a cognitive point of view, what I would like is other people to really understand it more. ... Nobody ever actually knows what MS is apart from if you're in a wheelchair. People think MS-wheelchair.

Grace: Even though we have cognitive problems, no one really understands what they are. Where I work, I've got another lass that's got MS. But she has a cane, so they understand it. They see it. . . . I can say, 'I've got MS', but they look at me and say, 'no you haven't' [laughing]. . . . I think a lot of it would be education to people.

Participants also wanted to raise awareness of communication changes associated with MS in workplaces to help promote access and inclusion. They indicated that workplace adjustments are often readily available for individuals with physical disabilities, but not for the invisible symptoms, including communication changes.

Felicity: Better awareness in workplaces. . . . If workplaces who actively promote diversity and disability inclusion were aware that this [communication changes] is something that people experience beyond the physical aspects of disability, then maybe they can employ kind of different supports to people with this form of symptom.

Jasmine: In the workplace it is stigmatized because people don't understand. . . . You don't know how to raise it [communication changes] because you may be unemployed or at best, you'll be shoved in the corner.

Subtheme 1.6: Geographically and economically accessible and navigable services

Several participants recalled their difficulty in accessing support to manage their communication changes due to not knowing who to see and limited guidance from their doctors. Participants wanted clear referral pathways to receive the right care, in the right place, at the right time from healthcare professionals experienced with communication and MS.

Isobel: It's very difficult to get any kind of support. . . . It's not like I'm not aware of it [SLP], but it's accessing it, and then you spend the rest of your days thinking, 'now who am I going to go to? Where am I going to go? . . . Is this person worth going to?'

Participants wanted supports and services to be economically and geographically accessible, and timely. All participants acknowledged long waiting times to access healthcare services.

Grace: Accessible so you can actually, like there's no use to waiting five years to get in.

All participants agreed that a subsidised or free service to help PwMS manage communication changes would be ideal. Participants outlined a variety of ways to promote economically accessible services in Australia, including accessing university clinics, the National Disability Insurance Scheme (NDIS) and advocating for SLP funding, and having Medicare bulk billing services.

Lily: This service [to manage communication changes], if it was free, or Medicare bulk-billed then it would be an even better idea.

Some participants mentioned that home-based services would be ideal to overcome physical barriers, travel costs and minimize fatigue.

Theme 2: Partnerships

Subtheme 2.1: Effective patient–physician interactions

Participants wanted to work towards building collaborative, responsive, and supportive partnerships between themselves and healthcare professionals. Equal partnerships were described as those where PwMS felt they were listened to, their concerns were acknowledged and appropriate supports were offered. All participants reported that healthcare professionals routinely asked about physical changes; however, neglected to ask about potential communication changes. Common to all participants was wanting healthcare professionals to routinely ask and initiate conversation about potential communication changes during consults.

Lily: [Neurologists] To actually say, 'how you going with your communication? How you going with that side of things?'

Emma: I had to really stress that you know, I was having cognitive difficulties . . . there's nothing mentioned about cognition, and these are neurologists. It's like the elephant in the

room, and no one talks about it and um it's just crazy. ... It's almost like taboo.

Overall participants were dissatisfied by their interactions with healthcare professionals in relation to their communication changes and recalled several unsuccessful interactions. Some participants reported they tried to initiate discussion with their healthcare professionals about their communication needs; however, they were dismissive and did not offer further support.

Betty: In terms of cognition, it was like, 'oh, write that down'. But not even, 'how is that affecting you?' Not even expanding. ... I don't know whether she didn't know what to ask or didn't want to know or, 'I just don't deal with that'.

Participants wanted health professionals to listen, as well as acknowledge and address concerns raised regarding their communication. Some participants highlighted that disparities can exist between the agenda of healthcare professionals and patients. Moreover, some participants acknowledged that MS symptoms can vary daily and that healthcare professionals may dismiss a patient's report if the symptom is not present and observable during the consult.

Isobel: I've found that quite often when you go to a neurologist, they are either really very busy or they just disregard some of the things you say to them ... here we are talking about communication ... that they [neurologists] actually listen, that they actually try and understand that it [communication changes] is a factor, and it is a factor that some of us might need some support with.

Anna: To believe ... you can say, 'I know I'm speaking perfectly right now, but you know these kinds of experiences I've been having at these times just makes it worse'. If you're in the office with them and they can't see it, you need to trust us, and even if you can't see it you need to treat us or give us referrals, give us advice, just take it as truth because it is.

Several participants suggested that they would find it helpful if healthcare professionals implemented strategies (e.g., writing key information) during consults to facilitate

their communication needs (e.g., difficulty remembering conversations and verbal information).

Daisy: Doctors not being so aware of some of the MS things, I mean if they are aware there can be communication issues, it would help if rather than leaving it up to you to say, 'I'm having trouble, I'm not going to remember this conversation'. If they said, 'okay, you know, some people with MS have some problems remembering things, coupled with communication, if you experience that I can write you notes, so I can email you notes'.

Subtheme 2.2: A multidisciplinary team-based approach

Participants recognized the complexity of managing communication changes associated with MS and highlighted the benefit of a team-based approach comprising various allied health professionals. The disciplines raised by participants included neuropsychology, SLP, psychology and occupational therapy. The benefits of neuropsychology that were discussed included having a comprehensive assessment of cognition to identify areas of strength and weaknesses, and to then use this information to develop personalized self-management strategies.

Emma: I think getting a referral to a neuropsychologist would be a good start. To confront your neurologist, 'this [cognition] is an issue', and um you're not going to back down from it. And say, 'could I please have a referral?'

The benefits of SLP that were discussed included learning self-management strategies to cope with communication changes. Speech-language pathologists may also have a role to play in facilitating support groups. One participant recalled her positive experience with SLP services.

Kate: The speech pathologist just helped me with some strategies to cope with it [communication changes]. There was no magic fix but being able to slow down, just even pause mid-sentence and completely change what I was going to say ... especially at work, it's really good. ... I wouldn't have learned how to do that if it wasn't, for you know, having speech pathology.

The benefits of psychology that were discussed included learning how to cope with the psychosocial impact of com-

munication changes, support for building confidence and self-esteem, and tips on how to disclose and discuss invisible MS symptoms with family, friends and colleagues.

Jasmine: Support from a psychologist about how to broach it ... how to um raise it with people who I don't know say in the workplace.

Grace: We need someone to help our emotional dealings with it too.

The benefits of occupational therapy that were discussed included adaptation of the home/work environment to facilitate effective thinking and communication, and to learn self-management strategies.

Felicity: An occupational therapist ... that do like home visits that they can maybe come to your home and like assess. Um they can give you practical tips related to your space ... they can give you like organizational tips to kind of streamline the way that you do somethings so that you're not muddled.

DISCUSSION

In this study we explored what PwMS want and need to better manage their communication changes using a qualitative methodological approach. The results identified a variety of unmet wants and needs of PwMS. Two main themes emerged from the data: (1) accessible knowledge and a holistic approach; and (2) partnerships.

In the first theme, participants outlined the specific types of supports and services they wanted to better manage their communication changes. These included supports and services that were designed to be informative, comprehensive, whole-person focused, routine, empowering, affordable and easy to access. Participants expressed frustration that medical consults and assessments frequently focused on physical and visible symptoms; often overlooking less visible symptoms such as communication changes. This finding is consistent with previous research that shows that cognitive symptoms can be under-emphasized in the clinical assessment of MS (Nabavi & Sangelaji, 2015). In the present study, all participants wanted routine assessment and monitoring of their communication skills, which may help to optimize management, enhance the individual's quality of life, and document and raise awareness of this invisible symptom (Mortensen et al., 2020; Nabavi & Sangelaji, 2015). Previous research has shown that PwMS have positive attitudes

towards and endorse routine cognitive testing (Mortensen et al., 2020), which was confirmed here. Baseline and annual screening, and baseline and periodic neuropsychology assessment has been recommended by a multidisciplinary expert panel, particularly in the presence of subjective complaints, positive screening scores or specific social or work situations (Meca-Lallana et al., 2021). It is important to note that while cognitive assessment tasks have the potential to pick-up language deficits, they may overlook and be less suited to detecting other communication difficulties such as speech, voice and fluency changes. Frontline healthcare professionals should ask PwMS about their communication ability and the impact on their quality of life. In addition, patient-reported outcome measures (PROMs)—e.g., the Speech Pathology-Specific Questionnaire for Persons with Multiple Sclerosis (SMS) (El-Wahsh et al., 2018) and the Communication and Language Assessment Questionnaire for Persons with Multiple Sclerosis (CLAMS) (El-Wahsh et al., 2020)—can be administered by healthcare professionals to help identify communication symptoms, which may warrant further assessment and management.

Future research can look at developing additional tools and guidelines for how communication changes in MS can be routinely assessed, managed and monitored. An area for future research could be to develop norm-referenced and standardized clinical measures to evaluate communication in MS. At present, there is no norm-referenced and standardized clinical measure to assess communication in MS in the English language. The Assessment for Pragmatic Ability and Cognitive substrates (APACS) is an available tool validated with Italian-speaking PwMS that assesses a range of communication domains (Arcara & Bambini, 2016). This tool has a reasonable administration time (35–40 min) and is easy to administer and score, hence it is well-suited for clinical use (Arcara & Bambini, 2016). Accordingly, a future research endeavour could be to translate this tool into English, develop normative data and to evaluate psychometric properties of the translated tool. Moreover, there is growing interest in discourse sampling and analysis in MS given its potential as a sensitive measure of communication effectiveness and ecological validity (i.e., reflective of everyday spoken communication) (Arnott et al., 1997; Arrondo et al., 2010; Sonkaya & Bayazit, 2018). Discourse analysis is a widely used measure in other conditions with cognitive and language deficits, such as traumatic brain injury (Togher, 2001), and has shown promising initial uses in MS (Arnott et al., 1997; Arrondo et al., 2010; Sonkaya & Bayazit, 2018). Accordingly, an area for future research could be to develop guidelines for discourse sampling and analysis in MS for the purposes of assessment, monitoring, goal-setting and evaluating treatment effectiveness.



In addition to assessment, participants also spoke of their desire for more information about communication changes associated with MS, as well as practical strategies to deal with communication changes (e.g., ways to find the right word to say) in the form of self-paced online programs, resources and activities. This supports previous research that self-management strategies and education programs are desired by PwMS, and have been shown to yield positive outcomes (Plow et al., 2011; Rae-Grant et al., 2011). However, there has been limited research investigating such intervention programs on communication in MS (Kristensson et al., 2021). Education and information provision on communication changes in MS should focus on potential symptoms, their impacts, triggers and factors that influence communication negatively (e.g., fatigue, stress, relapses, heat and illness), examples of self-management strategies, and pathways to supports and services (El-Wahsh et al., 2021a; Halstead et al., 2021). For example, healthcare professionals can refer to self-management strategies reported by PwMS to help manage communication changes (see the results section of the following referenced studies: Blaney & Lowe-Strong, 2009; Bringfelt et al., 2006; El-Wahsh et al., 2021a). Participants also wanted educational resources for key communication partners to better understand symptoms and to learn supportive communication strategies. Communication partner training programs are well-established in other neurological conditions such as stroke, traumatic brain injury and dementia with positive outcomes for both parties (Eggenberger et al., 2013; Simmons-Mackie et al., 2010; Togher et al., 2010). These established interventions provide a valuable starting point for developing communication partner training programs for PwMS.

All participants wanted to engage in a regular support group that focused on communication. As shown in post-stroke aphasia, support groups can provide opportunities for authentic communication interactions in a supported environment, help develop genuine friendships and confidence, and sharing of strategies and methods of coping amongst peers (Tregoe & Brown, 2013). All participants in this study described the therapeutic impact of participating in the focus groups and a desire to meet regularly. Further research may consider a co-design approach with PwMS, carers and allied health professionals to develop a support group specifically focused on communication, and to evaluate its effectiveness. The 'Living with Dysarthria' communication group program may be used as a starting point to develop a MS-specific communication support group (Mackenzie et al., 2012). Further, participants acknowledged the benefits of a holistic approach to intervention to facilitate communication, incorporating fatigue management, confidence-building and psychological well-being.

In the second theme, participants described the kinds of interactions they dreamed of having with healthcare professionals to better manage their communication changes. Whilst some spoke positively about their patient–physician interactions; many spoke negatively about their experiences. Many participants were dissatisfied with the level of information they received about communication changes associated with MS from their doctors and with how their communication concerns were managed. This finding is consistent with previous research (Thorne et al., 2004). Participants reported that communication between healthcare professionals and PwMS can be improved through collaborative partnerships, such as medical professionals acknowledging symptoms, providing adequate education and by acting upon concerns raised (e.g., making appropriate referrals). These findings are in line with a significant body of research exploring the patient–physician relationship. A recent literature review highlighted how a person-centred approach driven by positive communication and interpersonal skills by physicians can foster trust and lead to improved management, better health outcomes, increased adherence to treatment and better perceived quality of services (Chandra et al., 2018). These findings should encourage healthcare professionals to place good communication skills at the centre of quality patient–physician partnerships (Berman & Chutka, 2016). Participants also wanted a multidisciplinary team-based approach to help manage the breadth of their symptoms, including communication changes. These MS care models exist in some countries (Gallien et al., 2014; Soelberg Sorensen et al., 2019). Future work should seek to develop, implement and assess the effectiveness of multidisciplinary MS care models within the Australian healthcare system (Gallien et al., 2014; Soelberg Sorensen et al., 2019).

Limitations

Some factors may affect the generalizability of findings reported here. The online Zoom format may have biased the sample as only those with technology equipment and skills participated. This may also have deterred individuals with more severe communication changes. However, this data collection method allowed for recruitment from across the Australian states, capturing a range of perspectives and experiences and enabled data collection during the Covid-19 global pandemic. Furthermore, those who participated reported communication changes significant enough to impact on their everyday living and quality of life and so provided valuable insights into unmet wants and needs of PwMS with communication changes. It is also important to note that this study involved the

perspectives of 12 PwMS from Australia, and therefore the views of this restricted group of participants cannot be generalized to the overall MS population. Moreover, this study had a high representation of female participants compared to the approximate 3:1 female-to-male ratio (Harbo et al., 2013) and only explored the perspectives of people with relapsing-remitting MS. Nevertheless, this study provides an insightful starting point, and future research can consider exploring this topic in a broader sample.

CONCLUSIONS

This study identified a wide range of unmet wants and needs of PwMS regarding their communication changes. Participants wanted routine assessment, more information, a holistic approach to intervention, accessible services, support groups, greater awareness of invisible MS symptoms, effective patient–physician interactions, and a multidisciplinary team-based approach to intervention. Moving forward, this information can inform future development of supports and services to help PwMS better manage their communication changes; ultimately, seeking to reduce the negative impacts.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare with respect to the research, authorship and/or publication of this article.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are not publicly available in their entirety due to potentially identifying details, and therefore concerns over privacy and ethical restrictions. Direct quotations from participants are used extensively in this paper to illustrate how the themes and subthemes were derived.

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