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Exploring the Perspectives of Healthcare Consumers Towards the Integration of Nutrition in Routine Multiple Sclerosis Care: A Qualitative Study

Shoroog Allogmanny^{1,2}  | Anita Stefoska-Needham¹  | Yasmine Probst¹ 

¹School of Medical, Indigenous and Health Sciences, Faculty of Science, Medicine and Health, University of Wollongong, Wollongong, Australia | ²Clinical Nutrition Department, College of Applied Medical Sciences, Taibah University, Madinah, Saudi Arabia

Correspondence: Shoroog Allogmanny (sma030@uowmail.edu.au)

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ABSTRACT

Background: People living with multiple sclerosis (plwMS) expect to receive nutrition information from healthcare professionals (HCPs), to self-manage their disease. This study aimed to explore plwMS' experiences with nutrition-related care and generate an understanding of their needs and preferences for how it could be delivered in routine care.

Methods: This qualitative study, informed by an interpretive phenomenological approach, was undertaken using online focus groups with Australian adults living with MS. The discussions were recorded and transcribed verbatim. Transcribed data were analysed using an inductive, reflexive thematic analysis framework.

Results: Twenty-five plwMS participated in one of six focus group discussions. Three key themes and seven subthemes representing participants' experiences and needs were generated: (1) *nutrition guidance is overlooked in routine MS care* due to HCPs prioritising medication over nutrition, resulting in the perception that plwMS are their own nutrition educators; (2) *routine nutrition guidance is needed*, highlighting the desire to receive accessible and meaningful MS-related nutrition information from HCPs with nutrition knowledge for MS; and (3) *person-centred care is a priority*, highlighting the importance of acknowledging that no one-size-fits-all approach exists for plwMS, providing a holistic approach to the coordination of nutrition care and access to dietetic services.

Conclusions: This study generated insights into the gaps between the needs and experiences of plwMS with nutrition-related care during routine MS care, which may impact their MS journey. PlwMS seek credible, simple, consistent and MS-specific advice to be provided routinely for their care. Our findings underscore the need for individualised nutrition care from a nutrition-qualified HCP or dietitian.

1 | Introduction

Multiple sclerosis (MS) is a chronic neurodegenerative disease of the central nervous system that leads to non-traumatic disability in young adults [1]. The disease results in various neurological symptoms, such as fatigue, pain, sleep disturbance, bowel and bladder dysfunction and spasticity, ranging from

mild to severe [2] and short-term to long-lasting [3], compromising the quality-of-life of people living with MS (plwMS) [4]. In most cases, MS is characterised by symptom relapses followed by periods of remission, termed relapsing-remitting MS [5]. Additionally, comorbidities are common to plwMS, including depression, obesity, hypertension and diabetes [6]. Comorbidities are linked to symptom severity [7] and a higher

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Summary

- People living with multiple sclerosis (pwMS) are not receiving appropriate healthcare support to guide their nutrition journey.
- Challenges in access to dietetic services due to financial and geographical issues are evident.
- Healthcare professionals (HCPs), such as neurologists, general practitioners and nurses, can help to support the nutrition needs of pwMS by directly providing information and/or credible resources as part of routine care.
- Future research is required to explore HCPs' experiences and perspectives, to support nutrition care for pwMS. This would complement the findings from the perspectives of healthcare consumers (pwMS).

risk of disability progression [8]. Disease-modifying therapies (DMTs) are the first-line treatment for medically managing MS to reduce disease activity and slow disability progression; however, a cure remains elusive for MS [9].

Nutrition management, including consuming a balanced diet, can have promising beneficial effects for the MS disease course [10]. Tailored dietary changes combined with nutrition education can also help to manage MS-related metabolic comorbidities [11]. A recent systematic review of observational studies also concluded that a higher quality diet is associated with reduced MS disability and better quality-of-life; however, the effect of diet on other MS outcomes (e.g., fatigue, depression and relapse) remains inconclusive [12]. Despite a growing number of randomised controlled trials and systematic reviews on the impact of specific dietary interventions on MS outcomes, there is insufficient high-quality evidence to recommend a specific diet [13–16]. The current evidence highlights the need for further well-designed interventional studies to investigate associations between diet and MS outcomes.

Due to a lack of evidence for MS-specific nutritional guidelines, the general advice for pwMS is to follow country-specific national dietary guidelines to optimise nutritional status and reduce the risk of diet-related comorbidities [17]. According to both quantitative [18] and qualitative [19, 20] studies, pwMS are interested in nutrition and frequently modify their diets to gain a sense of control over and/or self-manage their disease. However, pwMS can easily access non-evidence-based health-related information from online sources [21], exposing them to nutrition advice that often contradicts the dietary guidelines [22]. A survey-based study revealed that pwMS wanted more information about health behaviour management, including nutrition, as part of their routine healthcare [23]. Further evidence indicates that while pwMS expect to receive routine nutrition information from trusted sources, such as healthcare professionals (HCPs), they are not receiving it [24, 25]. PwMS with unmet needs for nutrition information are more likely to seek non-evidence-based alternatives such as restrictive therapeutic diets that may increase their risk of nutritional deficiency [24].

Since regular monitoring for chronic diseases, such as MS, is part of routine care, it represents an ideal setting for

promoting and reinforcing evidence-based nutrition support. HCPs, such as general practitioners (GPs), neurologists and nurses, play a role in providing nutrition information and referring to dietitians as needed, given their regular interaction with pwMS during their routine care. HCPs must also address their patients' information needs, including nutrition-related queries [26]. Consideration of healthcare consumer voices (namely, pwMS) is important for generating opportunities to support nutrition care and enhance person-centred care [27]. The holistic World Health Organization's International Classification of Functioning, Disability, and Health framework has been developed to facilitate a shift from the biomedical model of medicine to a more holistic model of health [28]. This framework emphasises collaboration between researchers, HCPs and healthcare consumers as experts by experience in the development of health services and support [29]. Recently, researchers in Australia collaborated with pwMS and HCPs to improve patients' experiences by understanding the perspectives and needs for a self-guided nutrition educational programme [30]. The key output of this research was the codesign of an online MS nutrition education programme meeting pwMS' needs. Similarly, researchers in Germany engaged pwMS and HCPs to develop a nutritional booklet tailored to the information needs of pwMS [31]. These and other studies have enhanced our understanding of pwMS' needs for reliable and disease-specific information [19, 20, 30, 31], and highlighted their want for appropriate nutrition guidance from their HCPs team [24, 25].

While previous research suggests including HCPs such as dietitians to support the nutrition journey for pwMS, consumer experiences and needs are unclear in relation to routine patient-HCP interactions. Including healthcare consumers' (pwMS) voices to understand their living experiences and perceived needs will aid in designing a customised solution to enhance the accessibility of nutrition guidance in routine MS care. Therefore, this study aimed to explore the experiences of pwMS with nutrition-related care and generate an understanding of their needs and preferences for how it could be communicated or delivered in routine care.

2 | Methods

2.1 | Study Design

A qualitative descriptive study, informed by an interpretive phenomenological approach [32], was undertaken using focus group discussions. This approach was chosen to delve into participants' living experiences, needs and preferences for nutrition-related care, and to inform a consumer-driven solution [32]. The dynamic nature of focus group discussions enables the generation of diverse and rich insights through active interactions among participants [33]. Further, the discussions may trigger a recall of experiences [34, 35], beneficial to attention or memory difficulties common to some pwMS [36]. The study was conducted and reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines for qualitative studies [37] (see Table S1).

2.2 | Study Sampling and Recruitment

The inclusion criteria were (1) aged ≥ 18 years; (2) self-reported clinical diagnosis of MS, regardless of the MS phenotype, duration and severity; (3) no cognitive impairment preventing communication; (4) ability to converse in the English language; (5) access to the Internet; and (6) reside in Australia. Several recruitment strategies were employed to access a diverse group of potential participants [38]. Participants were recruited using convenience sampling by uploading study flyers to social media platforms and posting on websites of relevant not-for-profit professional MS organisations. The participants shared the study flyer with relevant contacts to maximise reach (snowball method) [39].

2.3 | Ethical Considerations

The University of Wollongong Human Research Ethics Committee approved the study (Approval number: 2023/307). Before the discussions commenced, all participants provided written and verbal informed consent. Participation in the focus group discussions was voluntary, and participants were informed about the nature of the discussions and their right to withdraw at any time. Each participant received an AU\$40 gift voucher to acknowledge their time.

The facilitators conducted the discussions in a respectful and inclusive environment, encouraging participants to respect others in the group. Participants were reassured that there were no right or wrong answers and were encouraged to share only what they felt comfortable disclosing. The research team had no personal relationship with the participants.

To protect participant confidentiality, all transcripts were de-identified before data analysis. Names and identifying information (e.g., age, gender, place) were removed, and this information in quotations was replaced with [X] to maintain anonymity. Participants were assigned pseudonyms, which included a participant number, focus group discussion number and years living with MS (e.g., P01, FGD1, 1 year).

2.4 | Data Collection

Data were collected between February and March 2024. The focus group discussions were conducted online using Zoom (version 5.9.1 <https://zoom.us>) to enable diverse geographical sampling and remove cost and travel barriers. A semi-structured discussion guide (see Table S2) was developed based on previous studies [19, 40] and research team expertise (S.A., A.S.N. and Y.P.). The guide included seven questions about participant experiences and needs for receiving nutrition care. Prompts and probes were used to encourage participation and gather additional detail [41]. Before the focus groups, feedback on the questions was sought from one person living with MS who did not participate in the focus groups and two dietitian experts in MS, leading to iterations as required. Participant sociodemographic data (gender, age, location, education level and employment status) and clinical data (MS type, years since

diagnosis, DMT use and physical disability using the Patient Determined Disease Steps [PDDS] [42]) were collected using a short questionnaire sent by email, which participants completed and returned.

The first focus group discussion was used as a pilot test to evaluate the comprehensiveness and understandability of the questions to participants. The transcript from the first focus group was included in the final analysis because the discussion guide did not change. A dietitian and doctoral researcher (S.A.) facilitated all of the focus groups, with the first focus group also facilitated by A.S.N., a dietitian and experienced qualitative researcher. Efforts were made to minimise group dynamics bias by actively encouraging all participants to share their experiences and views. The focus group discussions were recorded and transcribed verbatim using two recording options, Zoom and Otter AI software (version 2.1.59.697 <https://otter.ai>). Two independent researchers (S.A. and C.C.) verified the transcripts against the audio recordings for accuracy [43, 44] and de-identified all personal information.

2.5 | Data Analysis

The transcribed data were inductively analysed using the reflexive thematic analysis framework described by Braun and Clarke (a six-step process) [45]. Two researchers (S.A. and C.C.) independently read the transcripts for data familiarisation and systematically generated the initial codes. The researchers (S.A. and C.C.) met weekly to discuss and reflect on the coding process. The primary researcher (S.A.) then grouped codes into themes and subthemes, which were mapped based on related ideas. The themes were refined iteratively via feedback and discussion with the research team (S.A., A.S.N. and Y.P.) until a consensus was reached [45]. Data collection and analysis were conducted concurrently, focusing on achieving sufficient depth and richness of insights [46]. Recruitment was stopped after the sixth focus group discussion as this data set provided meaningful and rich insights. Transcript coding was managed using NVivo 12 software (QSR International Pty Ltd., Doncaster, Victoria, Australia).

2.6 | The Research Team and Reflexivity

The all-female research team consisted of three dietitian researchers (S.A., A.S.N. and Y.P.) and a student researcher enrolled in a medical health science programme (C.C.). S.A., C.C. and Y.P. had prior experience with MS-related research. A.S.N. had expertise in design-led qualitative research. The research team's diverse backgrounds ensured multiple perspectives were incorporated.

As dietitians, the authors acknowledge that their understanding of nutrition-related care and MS is shaped by their professional training and clinical experiences. To enhance the credibility and rigour of the findings, reflexivity was integrated throughout data collection, analysis and reporting [44]. The research team engaged in continuous reflection on their backgrounds and professional perspectives to remain mindful of their

positionality and its influence on the research process and data interpretation [47]. The senior researcher (Y.P.) is a person living with MS, and she had no direct contact with the participants to maintain a degree of interpretative distance. However, she remained actively engaged with the research team through reflexive discussions during both the data collection and analysis stages.

Peer debriefing between the primary researcher (S.A.) and the observer (C.C.) was conducted post-focus group discussions to reflect on personal observations, identify successful elements and suggest improvements for future discussions. Furthermore, peer debriefing of the findings was conducted with two research dietitians working in MS who did not contribute to the data collection and analysis. This fostered deeper reflexivity and interpretative engagement with the data, rather than aiming for validation. Similarly, a summary of the preliminary findings was shared with the participants via email, providing an opportunity for further reflection and engagement. Although four participants from different focus group discussions responded with no additional insights, the interpretation of findings remained researcher-led.

In line with Braun and Clarke's reflexive thematic analysis [45], we acknowledge that knowledge is actively co-constructed rather than objectively extracted from the data, and our subjectivity in interpreting the data does not detract from the quality of data analysis.

3 | Results

3.1 | Participant Characteristics

Twenty-five plwMS met the eligibility criteria and participated in one of six focus group discussions, five comprising 4–5 participants and one comprising three. The discussions ranged from 55 to 70 minutes. No carers or family members of the participants attended the discussions. Most participants were female ($n = 20$, 80%), and their mean age was 43.7 years. The participants resided in five states of Australia. Most participants reported having relapsing-remitting MS ($n = 20$, 80%), and the median time since MS diagnosis was 7 years. The final sample was diverse in terms of disability levels, as measured by the PDDS scale. Participants' disability levels ranged from zero (some mild symptoms that do not limit activity) to seven (a wheelchair is the main form of mobility), with a median scale of two (moderate disability without limitations in walking) [42]. Almost half ($n = 12$, 48%) of the participants chose not to take their prescribed DMTs due to side effects and/or a personal preference to use nutrition and diet to manage their MS. Table 1 summarises participants' self-reported characteristics.

3.2 | Key Themes

Thematic analysis of the data generated three key themes: (1) nutrition guidance is overlooked in routine MS care, (2) routine nutrition guidance is needed and (3) person-centred care is a priority. Subthemes were created within each key theme

(Figure 1), described in more detail below with supporting quotations.

As shown in Figure 1, the participant experiences in theme one shaped their perceived needs and preferences described in themes two and three.

TABLE 1 | Demographic and clinical characteristics of the participants with MS ($n = 25$).

Characteristics	
Gender, N (%)	
Woman/female	20 (80%)
Man/male	5 (20%)
Other	0
Age (years)	
Mean (SD)	43.7 (10.40)
Range	24–59
Geographic location, N (%)	
New South Wales	11 (44%)
Victoria	7 (28%)
Queensland	4 (16%)
Western Australia	2 (8%)
South Australia	1 (4%)
Highest level of education, N (%)	
Certificate III–IV	3 (12%)
Advanced diploma/diploma	6 (24%)
Bachelor's degree	10 (40%)
Postgraduate degree	6 (24%)
Employment status, N (%)	
Employed	18 (72%)
Disability pension	4 (16%)
Retired	3 (12%)
Type of MS, N (%)	
Relapsing-remitting MS	20 (80%)
Primary-progressive MS	3 (12%)
Secondary-progressive MS	2 (8%)
Time since diagnosis (years)	
Median (IQR)	7 (6.28–14.20)
Range	0.5–35
Currently on DMTs, N (%)	
Yes	13 (52%)
No	12 (48%)
PDDS level	
Median (IQR)	2 (1.69–3.51)
Range	0–7

Abbreviations: DMTs, disease modifying therapies; IQR, interquartile range; MS, multiple sclerosis; N , number; PDDS, patient determined disease steps; SD, standard deviation.

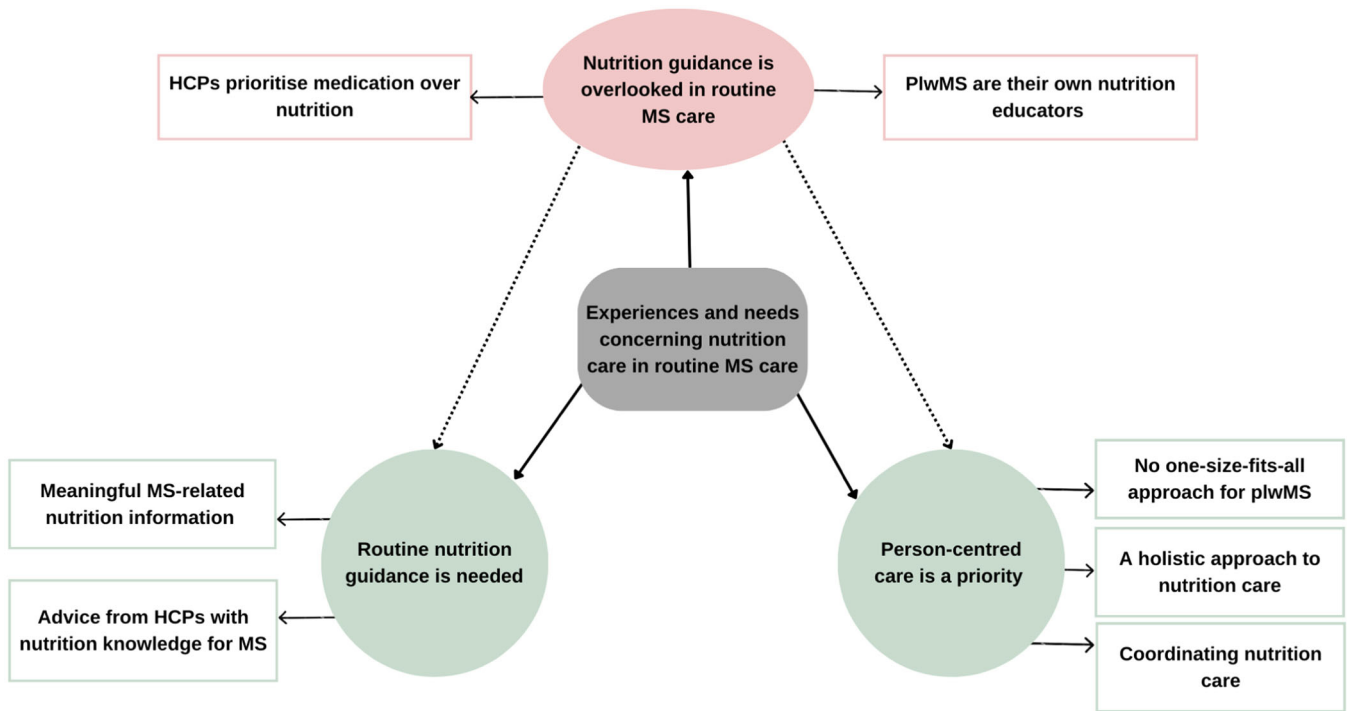


FIGURE 1 | Developed themes and subthemes from the thematic analysis of the focus group discussions with people living with multiple sclerosis. *Abbreviations:* HCPs, healthcare professionals; MS, multiple sclerosis; plwMS, people living with MS.

3.2.1 | Theme 1: Nutrition Guidance Is Overlooked in Routine MS Care

This theme consists of two subthemes that explain why nutrition is often overlooked in routine MS care.

3.2.1.1 | Subtheme 1A: HCPs Prioritise Medication Over Nutrition. Participants reported that while HCPs prioritise medication in MS clinical care, plwMS are motivated by and prioritise nutrition and diet for self-management. Participants were unanimously frustrated and dissatisfied with how many HCPs, particularly neurologists, GPs and nurses, did not acknowledge nutrition or diet in their management plans. Some participants reported asking questions to initiate conversations on MS and nutrition with their HCPs; however, HCPs were reported as being dismissive, suggesting diet as unimportant or irrelevant.

I asked initially about diet and was told that “it would do nothing to help me. It was a waste of time. Don’t even bother looking at it” pretty much my only option was medication. Yeah and that’s what my neurologist told me...You can control your diet, so you want them to support it. (P18, FGD5, 1.5 years)

Some participants described instances where HCPs addressed their queries. However, they were frustrated by a perceived lack of HCP knowledge because the information they received was overgeneralised and insufficient to their needs. This frustration reflected unmet expectations for specific information and guidance.

It [nutrition] doesn’t seem to come to the table when we get diagnosed with something, they say okay, go find a medication. Food is never really at the forefront and she [HCP] was really telling me nothing that I didn’t already know about, you know, healthy eating! (P15, FGD4, 4 years)

A lack of or limited support from HCPs and their prioritising of medication appeared to influence plwMS’ perceptions of their HCPs’ competence in nutrition management. Participants noted that this could be due to limited resources, low confidence or knowledge, and/or a lack of interest among HCPs in incorporating nutrition for MS into their routine practice.

They [HCPs] don’t talk about it [nutrition] because they don’t know. They don’t feel confident, like what they feel confident is the medical side of it [MS]. (P17, FGD4, 7 years)

Other participants discussed how the clinical appointment time might be a barrier to HCPs initiating and prioritising a conversation about nutrition for MS, suggesting limited time as a possible reason for a lack of support from HCPs.

In terms of the time factor that you have with GPs and neurologists, I don’t think apart from maybe 2 appointments in 11 years that I had more than 20 min with a neurologist. I think they’re time-poor. (P14, FGD4, 11 years)

About one-third of participants who had seen a dietitian shared their experiences of proactively seeking a referral from their GP

and/or neurologist. Due to the perceived limited support from HCPs, uncertainty around nutrition, specific dietary management and exposure to overgeneralised advice, plwMS are often self-referred to dietitians.

The condition [MS] that I'm living with, that I need advice on. It was just too general. Personally, I've sourced dietitian advice like, in the last couple of years, after having extreme fatigue from the disease-modifying therapy and gaining weight for the first time. (P24, FGD6, 33 years)

3.2.1.2 | Subtheme 1B: plwMS Are Their Own Nutrition Educators. The lack of or limited support and guidance from HCPs resulted in a perception that plwMS are their own nutrition educators. Participants shared their experiences of actively managing their MS by prioritising nutrition and seeking information from various sources (e.g., books, friends and online MS support groups) to guide their nutrition journey to make informed decisions.

All of the information I've ever found was up to me and so then I found that I was the one educating my GP and my neurologist...I think you find you have to be your own advocate. (P17, FGD4, 7 years)

Participants described the extensive cycle of research and self-education as challenging and time-consuming. The process of seeking advice was described as effort-intensive and overwhelming to navigate available information and identify information sources specific to MS.

It's [nutrition] taken me pretty much 4 years to get any straight advice on anything because there don't seem to be a lot of anyone out there who can really give much MS-based advice. (P15, FGD4, 4 years)

Participants mentioned facing challenges, including inconsistent and contradictory nutrition information, while independently seeking evidence-based and trustworthy information from various sources. This situation left them feeling lost and confused about sourcing accurate answers and information without HCPs' support.

So I read 3 books on MS diet, some contradict each other on things...I can't find anyone that can really answer that question succinctly. (P05, FGD1, 9.5 years)

Importantly, some participants voiced concerns that other plwMS may not have the capacity to self-source nutrition information to help guide their journey. A lack of nutrition awareness and proactivity, as well as limited resources, were identified as impediments to sourcing evidence-based nutrition information.

So that's what I mean like people who don't know about this stuff [nutrition] would not probably think to ask, but there's such a gap in the education there, it's just it's crazy. (P06, FGD2, 1.5 years)

3.2.2 | Theme 2: Routine Nutrition Guidance Is Needed

This theme consists of two subthemes that describe how plwMS want easily accessible and credible nutrition guidance to be delivered during their routine care.

3.2.2.1 | Subtheme 2A: Meaningful MS-Related Nutrition Information. Participants viewed nutrition as a valuable aspect of their MS journey, highlighting its importance for their overall well-being. They strongly wanted their HCPs to include meaningful nutrition-related conversations in their consultations regardless of their MS stage or duration.

Understand maybe not everybody needs dietary care that others might need, but at least discuss it in your consultations. (P23, FGD6, 17 years)

Participants preferred receiving information as positive messages about what they can eat and how to modify their nutrition rather than focusing on what they should avoid. Positive language was an important strategy to make plwMS feel supported and empowered instead of contributing to stress and anxiety about their nutrition and dietary choices.

It needs to be done in that respect, too, that you don't want to be told you can't have, but more a guide this... the things that might help rather than do this, and do that. But yeah, like, have you thought about frying this, more suggestions than you must. (P09, FGD3, 23 years)

Delivering advice in simple and straightforward information using plain language was considered optimal for plwMS who are in a complex and vulnerable situation. Participants also highlighted the importance of translating scientific evidence into understandable information when delivering nutrition advice to plwMS, especially those with low health literacy.

I would love for information to be in a really basic level to just help people...I mean some people especially when they've just been diagnosed and they are sick and they've got all this stuff running through their head... look it's great getting the oh, "there are research papers on this, there's this information on this" all this technical stuff, and some people like oh, my God, what the hell like! I'm so overwhelmed now, I don't know what to do. (P07, FGD2, 20 years)

Frustration about receiving irrelevant advice about MS was expressed. Therefore, participants strongly desired clear nutrition information specific to MS, emphasising the importance of consistent nutrition recommendations across HCPs.

It [nutrition advice] was nothing MS-specific, like, I said, I'm here for something MS-specific..., trying to find anything that was really consistent was just so difficult and then getting anything that was specific to what I needed. (P15, FGD4, 4 years)

Participants described the nutrition and diet topics they desired to receive information about, which did not differ according to the stage and duration of MS. Table 2 summarises these topics, with the most mentioned topics listed first.

Regardless of the recognition of insufficient time within clinical appointments, participants argued that it is the responsibility of HCPs to support them. This highlighted their expectation of HCPs as a key information source. Solutions, such as referral to centralised online educational resources or providing them with written pamphlets, were suggested to provide plwMS with easily accessible, evidence-based nutrition information.

I think it is by the time they've [HCPs] done their routine checks, and you know, written your referrals to go and do whatever you need to go and do next. You're really struggling, but that doesn't mean they couldn't be providing you with information for you to look for something. (P17, FGD4, 7 years)

3.2.2.2 | Subtheme 2B: Advice From HCPs With Nutrition Knowledge for MS. Overall, participants emphasised the importance of receiving nutrition advice from someone who can provide trustworthy and reliable nutrition information specifically for MS. While they recognised that detailed nutrition education is within the scope of dietitians, there was also a recognition that HCPs (e.g., GPs, neurologists and nurses) should have some basic knowledge about nutrition for MS to be able to meet their needs and help answer their questions. Therefore, they suggested that HCPs may benefit from 'professional development' training to equip them with knowledge about MS-related nutrition.

I kind of want them [HCPs] to understand a little bit. I'm not saying they [HCPs] need to be experts in it [nutrition], but they kind of you'd hope that they knew. (P23, FGD6, 17 years)

It is about education. I think the education probably needs to start with them [HCPs] first. (P14, FGD4, 11 years)

Specifically, participants had different opinions about the preferred HCP to provide nutrition advice in their routine clinical care. Many wanted to receive it through their GPs due to their frequency of contact, accessibility and time availability compared to other HCPs, such as neurologists.

The GP is the one that should be referring and talking to you about your nutrition and your MS..., because you would contact your GP. They're easier to contact, and you would see them more often. (P12, FGD3, 8 years)

While neurologists primarily focus on diagnosis and medical treatment, participants felt neurologists should provide at least basic nutrition advice because they are often the first HCPs to encounter patients after their MS diagnosis.

I also think you know it's worthwhile that a neurologist talks to you about it [nutrition]. (P21, FGD5, 5 years)

MS specialist nurses were highlighted as critical members of MS care teams, holistically providing continuous advice, education and support, and they can contact plwMS more frequently than neurologists. Therefore, participants felt that MS specialist nurses are well-placed to provide nutrition guidance.

My current neurologist has a really lovely MS nurse. So maybe it's about providing information to them, too, because they tend to have a bit more time to be able to spend with patients outside of the neurologist appointment. (P14, FGD4, 11 years)

However, some participants wanted to begin this care with a dietitian who has expertise in nutrition and is trained in medical nutrition therapy because they perceived other HCPs may not have knowledge and skills in nutrition.

I think that personally, I'd love to start off with a really, in-depth dietitian consultation..., but then, you know, discussing tracking of that with the GP..., but I need to, I think boost start with some solid information from you know, someone really knowledgeable in nutrition. (P19, FGD5, 0.5 year)

Several participants discussed dietitians as able to prescribe nutrition care plans and outlined their roles in providing nutrition counselling. They expressed a desire to continue dietetic consultations for practical and sustainable dietary management strategies.

Then a second step for me, as far as any health [advice] from a dietitian, for example, how to make that work for you. (P15, FGD4, 4 years)

In contrast, other participants recalled their difficulty in receiving dietetic care due to the cost and access to these services, particularly those living in rural areas. Participants felt that other HCPs must provide basic nutrition advice and guidance to fill this gap.

I've tried to see a dietitian there [location], but their starting appointments are 500 bucks..., and I don't have that money. (P13, FGD4, 35 years)

I live a little bit rural. I guess you'd consider [X], so for me accessing the service [dietetics] sort of just seeing how the path I'm taking at the minute will go. (P18, FGD5, 1.5 years)

Some participants suggested receiving nutrition consultations with MS-trained dietitians via telehealth to address some of the dietetic consultation barriers and make accessing dietetic services more convenient and cost-effective.

TABLE 2 | Overview of topics of interest raised by participants.

Topic	Exemplar quotation
Anti-inflammatory foods	<i>'Well, anti-inflammatory foods, because at the end of the day, we all know if that [inflammation] is inflamed... So we wanna keep inflammation down' (P20, FGD5, 7 years)</i>
Manipulation of gut microbiome with diets	<i>'Gut health stuff like how important gut health is and vagus nerve stuff I reckon it'd be really beneficial for a lot of people as I know that because it does still relate to diet' (P6, FGD2, 1.5 years)</i>
Managing metabolic comorbidities, including body weight and high cholesterol	<i>'It would be great for weight control and other blood contribution to other illnesses like cholesterol, we are trying to treat the whole person' (P5, FGD1, 9.5 years)</i>
Evidence-based nutrition recommendations	<i>'I would like to receive the latest evidence of what is credible and proven' (P24, FGD6, 33 years)</i>
Maintaining nutritional adequacy with supplements	<i>'I guess, affordable supplementation where your nutritional intake is inadequate' (P24, FGD6, 33 years)</i>
Easy cooking recipes when experiencing fatigue	<i>'You know when you're running out of energy. I would like a centre, a hub where there's just recipes, and people explain to me why these recipes are good or bad, whatever the case may be, so anything that can counteract the fatigue aspect' (P23, FGD6, 17 years)</i>
Saturated and unsaturated fats and its relation to MS	<i>'The old debates about saturated fat..., You know how much omegas but the building blocks like, if I make a change to say processed food elimination, that's a massive building block. What's the next? What are the other ones that are related to MS and from nutrition perspective?' (P20, FGD5, 7 years)</i>
Strengthening bone health with nutrition while on steroids	<i>'I would bring in bone health because little is known to me. Some MS medications take the calcium out of your bones and I end up with osteoporosis' (P16, FGD4, 23 years)</i>
Water intake and hydration	<i>'...in terms of diet, not a lot of people talk about your water intake which is quite a huge thing I find' (P14, FGD4, 11 years)</i>

Abbreviation: MS, multiple sclerosis.

It could have a link, a list of even telehealth dietitians who are really specialised in MS on that website. (P25, FGD6, 7 years)

3.2.3 | Theme 3: Person-Centred Care Is a Priority

This theme consists of three subthemes that explain how person-centred care should be achieved in routine MS care.

3.2.3.1 | Subtheme 3A: No One-Size-Fits-All Approach for plwMS. Participants described the journey of living with MS as highly personalised. They recognised that a one-size-fits-all approach does not work in this population, acknowledging that MS is a unique disease that requires an individualised approach.

We're all individuals. We all have our individual needs when it comes to nutrition. (P10, FGD3, 2 years)

Participants expressed a need for tailored nutrition advice to meet the specific needs of plwMS and ensure effective nutrition care. Advice approaches must consider the presence of MS-related symptoms and comorbidities that may impact nutrition

needs. Additional factors they considered important to address included age, mobility limitations and specific dietary needs.

I'm also a [X]-year-old, so I need to make sure that I had enough protein, calcium, you know everybody is individual so, and then other people might be celiac, so you know, they'd need to address the gluten factor, you know, so and then people may have reactions or allergies. (P08, FGD2, 7 years)

Aligning advice with a person's unique priorities and goals was also highlighted in the discussions, demonstrating the importance of tailoring nutrition guidance to support individual preferences.

It would be looking at what my particular goals and concerns are, and then working through a plan to meet those and sometimes that plan doesn't get fulfilled all at once. (P19, FGD5, 0.5 year)

A few participants also discussed the importance of considering the patient's readiness to receive nutrition information, especially those newly diagnosed with MS, given the tendency to be overwhelmed by the amount of information received at the time of diagnosis.

I think we should be very mindful to see if our patient is ready to receive it [nutrition advice] because then it might be even more reluctancy coming towards that area. (P20, FGD5, 7 years)

3.2.3.2 | Subtheme 3B: A Holistic Approach to Nutrition Care. Participants wanted to be managed as a whole person whose physical, mental and social circumstances are acknowledged rather than focusing solely on their MS. They considered this imperative in fostering comprehensive routine nutrition care for plwMS.

Stress...exercise, connection with your family..., so that they are appreciating you as an entire person with a condition, not a condition that's walked into the room. If you think about diabetes and diabetes management there's the drug management or the diet management or the exercise management, but they don't tend to all be captured as the same management plan. (P21, FGD5, 5 years)

Aspects, such as stress and mood changes, were recognised as interconnected factors that can impact the overall nutrition of plwMS. Participants discussed how awareness of these aspects and their effects on nutrition could improve the provision of nutrition advice.

Your mental health really goes tell you, if your mental health is not right, you know, you're not going to eat the right things...3 years ago, I lost my appetite, I lost my weight. (P11, FGD3, 6 years)

3.2.3.3 | Subtheme 3C: Coordinating Nutrition Care. Participants described the benefits of HCPs in coordinating nutrition care for plwMS by conducting comprehensive assessments, identifying needs and assisting with service applications, such as the National Disability Insurance Scheme (NDIS), to facilitate access to dietetic services, 'dietitians'. Receiving coordinated care services as part of routine MS care contributed to some participants viewing their experiences positively.

I've since had funded under NDIS..., due to a very good PT [physiotherapist] who did me an assessment and put in the application [for funding]..., were it not for that, I wouldn't have funding now either, and I probably wouldn't have followed up because it [dietetics service] can be very expensive as well. (P15, FGD4, 4 years)

The GP was considered to be central to the care of plwMS. Participants recognised the responsibility of GPs as gatekeepers to coordinate their nutrition care by identifying those who may benefit from specialised nutrition care and initiating referrals to a dietitian to support their nutrition journey.

You know your GP should know that you have MS, and the GP should be raising dietitian role and referral with you. (P10, FGD3, 2 years)

Additionally, participants highlighted the importance of collaboration between GPs and dietitians through effective communication to delegate professional responsibilities and improve the continuity of nutrition care for plwMS. The need for interprofessional collaboration was highlighted as a critical aspect to support ongoing nutritional management for plwMS due to the complexity of MS. This collaboration should involve sharing relevant information for ongoing monitoring and tailoring the nutritional plan for plwMS.

I would love that GP gives [nutrition] advice and [GP] to be able to take bloods to a dietitian...I find that super useful. (P05, FGD1, 9.5 years)

I think most of us have a fairly good GP,... and I like the idea of going to the dietitian first to get full like a full, set up for thingy, and then that to send and share to your GP. (P20, FGD5, 7 years)

4 | Discussion

This qualitative study explored plwMS' experiences with nutrition-related care and their needs for how it could be provided during routine care. Our findings suggest that better nutrition guidance is needed to improve plwMS' experiences throughout their MS journey. An HCP team involved in MS care could support the nutrition information needs of plwMS by directly providing them with information and/or credible resources. Furthermore, this team could facilitate access to dietetic services for personalised nutrition care and support person-centred care for plwMS.

As plwMS routinely interact with HCPs, they are generally dissatisfied with how nutrition advice, or the lack thereof, is discussed during routine healthcare interactions. The experiences described by our participants are consistent with previous studies that suggest plwMS are dissatisfied with the limited HCP conversations about nutrition [25] and exercise [48]. This drives plwMS to seek nutrition information from different sources, placing them at risk of unreliable and often conflicting advice. Our findings align with previous studies on plwMS and self-management [19, 20, 25], confirming that plwMS prioritise dietary self-management. Interestingly, some of our participants used nutrition and diet to self-manage their MS, while others adopted holistic management, integrating nutrition management alongside DMTs. Regardless of this behaviour, we did not observe any differences between our participants in their described need for nutrition information. Similarly, participant experiences with and their needs/wants for nutrition-related care also did not differ between those who were newly diagnosed and those with long-lasting MS.

The need for better nutrition guidance was expressed by our participants and resulted from a lack of, or limited, guidance throughout their MS journey. Given these findings, HCPs, such

as GPs, neurologists and MS specialist nurses, should try to meet the nutrition advice needs of plwMS, starting at diagnosis and continuing throughout their MS journey. However, our study highlights that many HCPs are not supporting this health behaviour and lifestyle management approach, primarily focusing on medical management. A recent qualitative study involving Australian HCPs revealed that external factors, such as training and skills, may impact HCP practices toward supporting lifestyle-related behaviour changes for plwMS in the context of brain health [49]. Our participants also perceived HCPs to have inadequate training and/or insufficient knowledge to provide MS-related nutrition advice, potentially explaining their focus on medication. Additionally, healthcare system barriers, including time constraints and limited resources, could limit HCP guidance, as our participants noted. Nonetheless, the barriers HCPs encounter in effectively supporting the nutrition information needs of plwMS remain unclear and further research exploring HCPs' experiences and perspectives is required. Such research will improve our understanding of the barriers and needs of HCPs in addressing the nutritional needs of plwMS.

Our study suggests that plwMS have no specific preference for which HCP delivers their nutrition advice in routine care. The participants agreed that all HCPs involved in MS care should have basic nutrition knowledge for MS and are responsible for meeting their information needs and addressing their questions as part of routine care. Existing studies have highlighted the importance of clear and MS-specific nutrition advice for plwMS [19, 20, 30, 31], and our findings highlight that challenges persist in translating this into routine MS care. These challenges motivate plwMS to receive credible, consistent and MS-specific nutrition advice beyond healthy eating. Most of the nutrition topics of interest raised by our participants were consistent with the national dietary guideline recommendations. However, plwMS desired this advice to be tailored to their unique experiences of MS. This observation may provide useful guidance for HCPs, including dietitians, to meet the preferences of plwMS by connecting the current dietary recommendations to specific health concerns and/or goals. For example, this advice could highlight how a balanced diet benefits MS outcomes by improving quality of life, and reducing disease progression, comorbidities and malnutrition risk. Delivering this advice in simple terms with motivational language was noted as essential for plwMS. Positive phrases can improve patient health outcomes [50], and simple advice can be more easily recalled and understood [51]. This is particularly important for plwMS, who may face cognitive impairment or have lower health literacy [52]. Additionally, providing educational materials is recommended to improve information retention at medical consultations, especially for patients with lower health literacy [51] and may also overcome the challenge of limited consultation time [53]. These findings provide a foundation for designing and creating targeted educational materials for plwMS that align with their needs and preferences.

Another key contribution of our study is that plwMS expressed a need for dietetic care from a nutrition-qualified HCP or a 'dietitian'. This observation was also highlighted in a study by Somerville et al. involving Australian healthcare consumers, including those living with chronic diseases [40]. Their study

identified dietitians as the most qualified HCPs to provide nutrition care. Our participants also wanted ongoing follow-up with dietitians to meet their individual needs and sustain their behaviour changes. However, some expressed a preference to begin this care by receiving nutrition advice from dietitians before receiving ongoing routine nutrition support from other HCPs. Despite limited, or no HCP guidance, only some of our participants had been able to access dietetic services since their MS diagnosis. Similarly, a survey study found that only 8% of respondents living with MS had received nutrition care from dietitians [54]. The participants in our study described their challenges in accessing this service due to financial and geographical barriers, potentially explaining why most participants in our study preferred to begin receiving nutrition guidance during their routine care from more accessible HCPs at a lower cost, such as GPs and MS specialist nurses.

This research provides new insights into plwMS and nutrition needs. Our findings suggest that plwMS can have different evolving needs over time due to MS-related symptoms, comorbidities and/or medication side effects. Therefore, providing nutrition information to plwMS should not be treated as a one-time routine care interaction but as an ongoing process that is integrated into routine MS care. This could include continued reviews during clinical consultations and/or follow-up calls and providing printed or online educational materials as needed. Furthermore, HCPs could coordinate nutrition care by referring plwMS to dietitians when indicated and facilitating their access to national insurance (e.g., NDIS) to meet their different needs. A study noted that working in a multidisciplinary setting with dietitians fostered interprofessional collaboration and enabled time-efficient dietitian referrals [55]. Further, a systematic review and meta-analysis found that interprofessional collaboration can improve the clinical outcomes of patients living with chronic diseases [56]. The implication for the GPs and other trusted HCPs in MS care, such as neurologists and MS specialist nurses, is to consider when to refer plwMS to a dietitian. Moreover, for plwMS who require dietetic care, continuous collaborative discussions between non-dietitian HCPs and dietitians are needed to detect early nutrition-related problems and monitor progress toward patient goals and needs. This approach can support achieving person-centred care by promoting coordination of holistic nutrition care and considers the specific individual needs of plwMS with a nutrition-qualified HCP or a dietitian. However, our findings suggest efforts are required to improve the accessibility of dietetic services for plwMS, such as advocating for policies that support funding and resources for dietetic services.

4.1 | Strengths and Limitations

A strength of our study is the diversity of the participants involved in its focus group discussions, including their varied clinical characteristics (time since diagnosis and disability levels) and geographical location within Australia. This diversity contributed to rich data, allowing us to capture a broad range of experiences and perspectives of plwMS with nutrition-related care. We used well-established procedures for data generation and analysis to ensure rigour and trustworthiness through reflexivity and transparency. While the researchers' dietetic

background enabled an in-depth and insightful engagement with the topic, the participation of a final-year medical research student without nutrition training in regular reflexivity activities introduced a different perspective, enriching the interpretation of the data.

Our study had some limitations that should be acknowledged. First, the study sample had a high representation of females, which was expected since MS predominantly affects females [5]. Second, as participants self-selected into this study [57], those who chose to participate in the focus group discussions may have been more interested in nutrition than those who did not participate, potentially influencing the perspectives shared. Given the context-specific nature of this study, our findings provide insights relevant to the Australian healthcare system, rather than being broadly transferable to other contexts.

5 | Conclusions

This study generated insights into the gaps between the needs and experiences of plwMS with nutrition-related care during routine MS care, which may impact their MS journey. Our findings have highlighted that plwMS seek credible, simple, consistent and MS-specific advice to be provided routinely for their care and prefer to receive it from HCPs with MS-related nutrition knowledge. In addition, while our findings underscore the need for personalised nutrition care plans from a nutrition-qualified HCP or dietitian, plwMS face evident challenges in accessing dietetic services. Although our study provides insight into the experiences and needs of plwMS for nutrition-related care, further research is required to explore HCPs' experiences and perspectives, to support nutrition care for plwMS. Together with our current findings, this could potentially inform tailored solutions for both plwMS and HCPs to support integrating nutrition into routine MS care, including access to dietetic services for personalised care plans.

Author Contributions

Shoroog Allogmanny, Anita Stefoska-Needham and Yasmine Probst were involved in the conception and design of the study. Shoroog Allogmanny and Anita Stefoska-Needham collected the data, with major contributions from Shoroog Allogmanny. Shoroog Allogmanny was responsible for data collection and transcription. Shoroog Allogmanny took a leading role in the analysis process and was responsible for writing and revising the manuscripts. Anita Stefoska-Needham and Yasmine Probst contributed with critical revisions during data analysis and contributed to the manuscript writing, reviewing and editing. All authors reviewed and approved the final manuscript.

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approaches within the MS community; however, the abbreviation 'plwMS' has been respectfully used in this article for brevity. The term 'lived experience' is commonly used in the literature; however, we used 'living experience' to acknowledge that MS is a lifelong condition.

Ethics Statement

The University of Wollongong Human Research Ethics Committee approved the study (Approval number: 2023/307).

Conflicts of Interest

Yasmine Probst declares that she is a person living with MS. Yasmine has received honoraria from MS Australia and MS Plus, is supported by a fellowship funded by MS Australia, and contributes to MS Australia advisory panels. Yasmine had no contact with the participants and was not involved in facilitating focus groups or analysing the transcripts. Shoroog and Anita declare that there are no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.