

**Title:** Dietary responses to a multiple sclerosis diagnosis: a qualitative study

**Running title:** Dietary attitudes and multiple sclerosis

**Authors:** Rebecca D Russell<sup>1</sup>, Lucinda J Black<sup>1</sup>, Jill Sherriff<sup>1</sup>, Andrea Begley<sup>1</sup>.

<sup>1</sup>School of Public Health, Curtin University, Perth WA, Australia

**Correspondence:** Dr Andrea Begley, School of Public Health, Curtin University, PO Box U1987, Perth WA 6845 Australia. Telephone +61 8 9266 2773. Fax +61 8 9266 2958. Email [a.begley@curtin.edu.au](mailto:a.begley@curtin.edu.au)

**Abstract****Background/Objectives:**

Multiple sclerosis (MS) is an immune-mediated disease with no known cure and insufficient evidence to support a special therapeutic diet to alter symptom management or disease progression. Several studies have reported dietary changes made by people with MS, but there has been limited investigation into experiences surrounding diet in those recently diagnosed. This study explored responses to diet after a recent diagnosis of MS in people living in Western Australia.

**Subjects/Methods:**

Eleven adults with MS (mean time since diagnosis 8 months) participated in semi-structured interviews focusing on responses to diet since MS diagnosis. Interviews were transcribed, coded and analysed using grounded theory principles.

**Results:**

Three theme responses emerged; 1) the perceived incompatibility of lack of/or generalised dietary advice with disease seriousness at the time of diagnosis; 2) extensive personal research and information seeking with difficulty judging credibility and 3) self-experimentation with diet to either control MS symptoms or to cure MS.

**Conclusions:**

Given the seriousness of the disease, there is a perceived gap in dietary information provided at the time of diagnosis. Healthcare professionals should address concerns with alternative therapeutic diets advertised to treat or cure MS, and clearly convey the reasoning for the general healthy dietary recommendations. This would better align advice with the perceptions about the role of diet in MS, assist people with MS in need of information and minimise dietary self-experimentation. Future research should explore the importance of diet for those who have had MS for a longer period of time.

**Keywords:** nutrition, dietary attitudes, qualitative, semi-structured interviews.

## Introduction

Multiple sclerosis (MS) is an immune-mediated disease characterised by the inflammatory damage and formation of scars on the myelin sheaths of the central nervous system axons.<sup>1</sup> The destruction of neurons and subsequent sclerosis can result in a wide range of symptoms due to the disturbance of neurological signal transmission, including cognitive decline, blurred vision, speech impairment, muscle weakness and tremors, bladder and bowel dysfunction, and fatigue.<sup>2</sup> The most common form of MS is the relapsing-remitting form, where people with MS (PwMS) have episodic relapses in which a sudden onset or increase in symptoms occurs. This makes the disease unpredictable. The cause of MS remains unknown and there is no known cure; however medication is used to manage disease progression. MS is one of the most common causes of neurological disability in young adults worldwide, second only to traumatic brain injury.<sup>3</sup> The disease affects at least 2.3 million people globally<sup>4</sup> and the prevalence in Australia is estimated to be 95.2 per 100 000 inhabitants.<sup>5</sup> The most frequent age of onset is between 20 and 40 years and, in Australia, women are three times more likely to have the disease than men.<sup>5</sup>

Several reviews have examined the role of diet therapy on the management of MS symptoms and disease progression including two systematic reviews<sup>6, 7</sup> and several scoping or short reviews.<sup>8-14</sup> Evidence for a therapeutic diet for MS is insufficient and dietary advice for PwMS is to consume a healthy diet in line with national dietary guidelines.<sup>7</sup> The aims of this advice is to improve the wellbeing and sense of control in PwMS.<sup>15</sup> Very few Australian adults achieve the national dietary guidelines as assessed in the 2011-12 National Nutrition Survey.<sup>16, 17</sup> It is estimated that up to 42% of PwMS across the United States,<sup>15, 18</sup> Germany,<sup>19, 20</sup> and Australia<sup>21, 22</sup> report making dietary changes after being diagnosed, however these changes are not always in line with recommendations and little is known about the reasons for change. There are alternative therapeutic diets who purport to modulate the inflammatory response of the disease<sup>23</sup> and a range of complementary and alternative medicine (CAM) uses documented in PwMS.<sup>24</sup> Alternative therapeutic diets such

as those promoted by Jelinek<sup>25</sup> and Wahls<sup>26</sup> in addition to CAMs<sup>24</sup> are being promoted for PwMS with no or limited evidence of efficacy.<sup>7</sup>

Qualitative research assists in our understanding of people's experiences and behaviours with disease and the meanings that people ascribe to these experiences and behaviours in the context of their everyday lives and social environments.<sup>27</sup> There is limited research on the reasons for making dietary changes in PwMS and to our knowledge, only one published qualitative study has explored the impact of MS on dietary behaviours,<sup>28</sup> however the study suffered from a number of rigour issues,<sup>27</sup> such as no statement on theoretical perspective or data saturation.

Exploring how PwMS respond to the dietary advice provided at diagnosis and what type of advice is needed will inform the development of resources and programs to improve healthy dietary intakes. Therefore, there is a need to further investigate how a diagnosis of MS changes the priority placed on diet, the reasons for any dietary modifications adopted, and the sources of dietary information that are accessed. The aim of this study was to explore the experiences with diet after a recent diagnosis of MS in people living in Western Australia (WA).

## **Materials and Methods**

### **Study design**

Due to the lack of previous research in this area, we used a qualitative methodology, guided by grounded theory principles. Grounded theory is useful when no prior theory about behaviours exists and researchers aim to broadly inductively develop a general explanation.<sup>27</sup> In this study the focus was on the experiences and responses (attitudes, beliefs and actions) related to diet after an MS diagnosis.

### **Participants and recruitment**

Purposive sampling was undertaken with potential participants contacted through a non-profit MS organisation, Multiple Sclerosis Society of Western Australia (MSWA). MSWA is a

primary service and support provider for people with neurological conditions living in WA and had appropriately 2400 members at the time of the research (General Manager Member Services, Personal communication). Participants met the inclusion criteria if they were adults (age  $\geq 18$  years), with a medical diagnosis of MS within the previous 15 months, living in WA, spoke English as their primary language, and were not pregnant. MSWA contacted members who potentially met the inclusion criteria by email with a brief purpose of the research and contact details of the researchers. Interested PwMS were provided with detailed information about the study and given the opportunity to ask questions via email or phone. A second email was sent by MSWA to increase participant numbers. In total, 18 people contacted the researchers, however five either did not meet the months since diagnosis criteria or did not respond to the further information sent. Participants were offered an AUD\$20 department store voucher to compensate for their time. We used limited disclosure, where the participants were informed of the study aim, but specific objectives were not disclosed. Written informed consent was obtained, stating pseudonyms would be assigned for anonymity. The study was approved by the Human Research Ethics Committee of Curtin University (Approval number HRE2017-0395).

## **Data collection**

Individual interviews were chosen to enable in-depth exploration of each person's MS experience and how they responded to dietary information surrounding their diagnosis. An interview guide (Table 1) was developed with input from the research team (two nutritionists and two dietitians) and the General Manager of Member Services at MSWA. Questions from other qualitative studies were reviewed including a) two studies (one published and one higher degree) exploring dietary behaviours of individuals with MS,<sup>28, 29</sup> b) dietary perceptions from people with cancer,<sup>30</sup> and c) general barriers and facilitators to a healthy diet for adults.<sup>31, 32</sup> In order to assess the interview duration and feasibility of the interview guide, the first author (RR) piloted the interview guide on two PwMS whose data were not

included in the analysis. Interviewing techniques and the guide were then revised under the guidance of an experienced qualitative researcher (AB).

**Table 1** Interview question guide

Topics	Discussion guide
Introduction and icebreaker	<p>How long have you been a Member of MSWA?</p> <p>Have you found MSWA to be helpful and a valuable resource?</p> <p>Generally, do you think that PwMS have different nutritional needs than adults? [Why/why not?]</p> <p>Did you feel there was an expectation that what you were eating and drinking was something you should or shouldn't be considering after your diagnosis?</p>
Diet and MS	<p>Can you tell me about any current nutrition guidelines for the general population?</p> <p>How do you think they apply to you?</p> <p>What do you think constitutes a healthy diet for PwMS?</p> <p>Has being diagnosed with MS influenced your food intake and what you eat? [Why/why not?]</p> <p>Or has it changed how you want to eat? [Why/why not?]</p> <p>Do you feel that diet affects your MS in any way? [Probe: specific types of foods, meals, timing of foods, symptoms]</p> <p>Do you feel that MS affects your diet? [Probe: side effects from medications, MS symptoms]</p>
Current diet and influences	<p>Think about what you eat on a 'usual or normal' day. Can you describe this to me?</p> <p>Is this very different to what it was like before your diagnosis? [How so?]</p> <p>Since your diagnosis, have you made any significant changes or followed a particular way of eating?</p> <ul style="list-style-type: none"> <li>○ How do you know if a dietary pattern you're following works for you?</li> <li>○ Can you tell me about of any diets for MS you've heard about?</li> </ul> <p>What are the most important factors that influence the food and drink choices you make? [Probe: time, cost, taste, convenience]</p>
Barriers	<p>How confident are you in regards to making healthy food choices?</p> <p>What would make you more confident?</p> <p>What things might make healthy challenging for you at times? [Probe: family situation, food literacy skills, MS symptoms]</p> <p>What things make healthy eating easier for you?</p>
Sources of information	<p>Where do you go for information about how to make healthier food choices? [Probe: Google search, ask health professionals, friends]</p> <p>How do you assess whether this is information you can trust?</p> <p>Has a health professional ever recommended a specific diet to you? [If so]</p> <p>What did they recommend and did they explain why?</p> <p>[If not] Did they explain why not?</p>
Resources	<p>Do you think there has been enough nutrition information and support provided to you to make healthy food choices? [Why/why not?]</p> <p>What do you think is missing?</p> <p>If you could choose any format at all and access it anywhere, how would you best like access any information about diet for MS?</p>
Conclusion	<p>Overall how important is the food and drinks you eat to your overall MS management?</p> <p>Anything else you'd like to add that we haven't covered?</p>

The interviews took place in a private meeting room at the MSWA facilities in 2017 by the first author (RR) or by videoconference using the Internet software application Skype for participants unable to travel (version 7.58, Microsoft Corp., Luxembourg). Probing was used to elicit further information as required. All interviews were digitally recorded and transcribed verbatim within 24 hours of interview completion, and memos were written reflecting on data analysis processes in response to emerging codes as part of a reflexive process. Member checking was used where participants could have their transcripts posted to them to ensure the data were accurately transcribed, and satisfactorily reflected their views and opinions. The recruitment, data collection and analysis process continued until data saturation was reached. Data saturation, where no new relevant results emerged from the data<sup>27</sup>, was reached after the ninth interview and an additional two interviews were conducted to confirm this point in the analysis. The average interview time was 54 minutes.

### **Data analysis**

Data were analysed using a grounded theory approach, where analysis commenced after the first interview in an iterative process using a constant comparative technique.<sup>33</sup> NVivo software (version 11.4.0, QSR International Pty Ltd) facilitated data organisation. The transcripts were examined line-by-line by the interviewer (RR) to identify words, phrases, and states of mind of significance to generate initial codes in an open coding process. Both literal and interpretive coding was undertaken, referring to coding direct observations from the data, and what was inferred from the data, respectively.<sup>33</sup> After theoretical saturation was reached on the completion of open-coding, we conducted a brief literature review on diet and other chronic diseases, as recommended by Charmaz.<sup>34</sup> As the analysis progressed, the theoretical perspective of social constructivism was applied to the emerging themes, where illness is constructed through the understanding of social realities resulting in multiple realities about the meaning of a disease and impact on everyday life.<sup>35</sup> Expert medical knowledge can influence patients' behaviours and their experiences with how they construct

meaning of their illness, particularly in creating lay knowledge and explanations.<sup>36</sup> The initial codes were grouped into categories and subcategories based on similarities and differences, then narrowed down and organised into themes. Peer debriefing was used to confirm the emerging themes by an experienced qualitative researcher (AB) and then broadly discussed with the research team in a number of meetings focused on emerging codes and questions to be explored in successive interviews.<sup>37</sup> Discrepancies in coding were discussed and resolved by returning to the data. The final themes were discussed with the General Manager of MSWA who was independent to the research to assess their confirmability.

## Results

### Participants' characteristics

Eleven PwMS, two men and nine women participated in this study. Participants had been diagnosed with MS for an average of eight months (range 3-15 months), and their average age was 47 years (range 31-70 years). Most participants were married (73%) and employed (91%). Table 2 presents the self-reported characteristics of the participants.

**Table 2** Participant characteristics ( $n=11$ )

Participant characteristics	
Sex $n$ (%)	
Male	2 (18%)
Female	9 (82%)
Age (years) mean $\pm$ SD	47 $\pm$ 13
Country of birth $n$ (%)	
Australia	7 (64%)
Other	4 (36%)
Marital status $n$ (%)	
Married	8 (73%)
Other	3 (27%)
Living arrangements $n$ (%)	
With spouse/partner	5 (45%)
With spouse/partner and children	3 (27%)



Other	3 (27%)
Number living in household <i>n</i> (%)	
1-3	8 (73%)
4+	3 (27%)
Employment status <i>n</i> (%)	
Employed	10 (91%)
Retired	1 (9%)
Type of MS <i>n</i> (%)	
Relapsing-remitting	9 (82%)
Other	2 (18%)
Time since diagnosis (months) mean $\pm$ SD	8 $\pm$ 5
Regular medication use for MS <i>n</i> (%)	
Yes	8 (73%)
No	3 (27%)
Interview duration (minutes) mean (range)	54 (23 – 78)

SD: standard deviation; MS: multiple sclerosis.

## Themes

Three key themes emerged from the analysis as responses specific to diet in PwMS. Firstly, there was a perceived incompatibility of the lack of/or generalised dietary advice considering disease seriousness at the time of diagnosis, secondly, extensive personal research and information seeking with difficulty judging credibility and the final theme was one of self-experimentation with diet to either control MS symptoms or cure MS. Excerpts from interviews are presented in Table 3, with pseudonym and time since diagnosis after each quote.

**Table 3** Diet response themes to MS diagnosis

<i>Perceived incompatibility of lack of/or generalised dietary advice with disease seriousness</i>
“Make sure you have a healthy diet, but that was about as technical as it got. Um it was like so OK what is a healthy diet.” (Carla, 12 months since diagnosis)
“It was only when I read um about this [diets], and I thought to myself well why wasn't I given any of this sort of information, or advised to you know, look into this when I was first diagnosed.” (Isabelle, 9 months since diagnosis)
“Without saying anything else, my guess is what he's saying is there is nothing else... Medical professionals are like that, if there's not direct evidence, um, they generally don't try and speculate put something in patients' minds.” (Murray, 15 months since diagnosis)

“None of the doctors that I’ve spoken to put any weight on an association with MS and diet, um, but they’re- they’re kind of not really [pause], I don’t think they’re really the right people to ask.” (Deb, 12 months since diagnosis)

“They (neurologists) don’t, they don’t understand that nutrition has such a big impact, and they don’t seem to want to, um, learn.” (Jessica, 4 months since diagnosis)

*Diagnosis-driven extensive information-seeking behaviour*

I have this overwhelming need to search everything (Deb, 12 months since diagnosis)

I’ve done a lot of research actually into what I should and shouldn’t be eating (Donna, 4 months since diagnosis)

“Professor Jelinek... His mother died after being diagnosed with MS, you know, he had it himself, and like I said by all accounts he’s cured himself so you know, you have to think that there’s something in you know, what he’s published.” (Isabelle, 9 months since diagnosis)

*Self-experimentation with diet to either control MS symptoms or to cure MS*

I think for me, um, I’d doing this as a self-discovery journey (Alicia, 4 months since diagnosis)

I generally think to try things I’ve got nothing to lose (Deb, 12 months since diagnosis)

“You’ve always got it [MS] in your DNA, you’ve always got the the bullet um, but it’s the poor lifestyle, bad gut health that pulls the trigger... If I had a clean lifestyle before I probably never would have got MS.” (Jessica, 4 months since diagnosis)

“I feel in control... the disease; it’s not controlling me... It’s [diet’s] the only aspect of the sort of management of it that I do myself... Diet is an everyday thing that I can take control of.” (Carla, 12 months since diagnosis)

*Theme 1 Perceived incompatibility of lack of/or general dietary advice considering disease seriousness*

All participants recalled that at the time of their diagnosis, there was very little discussion about what they should do about diet. If general dietary advice was provided by the neurologist, it was perceived as vague and not specific enough to MS. Participants were frustrated by this lack of specific dietary advice, particularly given the seriousness and incurability of their disease diagnosis. Participants either accepted they needed to follow national dietary guidelines if this was discussed or were dismissive of this advice. The former trusted that their neurologist or MSWA would provide information regarding dietary changes that might help their MS and didn’t ask further questions. Participants who dismissed perceived scant dietary advice such as ‘be aware of it’ assumed the lack of

information reflected a lack of knowledge about the link between diet and MS by health professionals. They were convinced there had to be something more to diet, however participants had difficulty articulating what a healthy diet actually was.

*Theme 2 Extensive personal research and information seeking with difficulty judging credibility*

Not receiving enough dietary advice at diagnosis led seven participants to search for their own information. Participants referred to a wide range of sources, including the Internet, friends, family, other PwMS, chiropractors and naturopaths, but rarely mentioned MS organisations or dietitians. The internet opened up a multitude of alternative diets and foods for MS including those promoted by doctors (Jelinek, Wahls). This contributed to the frustration that their disease wasn't being taken seriously by people and organisations they felt should be able to provide more specific dietary advice.

Eight participants found it difficult to decide what information was credible, with some describing the decision-making process as a 'gut feeling' or 'judgement call', but most mentioned checking the credentials of the author. The information was perceived as reliable if the author/s had a suitable qualification. Examples of this were diets promoted by Professor Jelinek and Dr Wahls who were often referred to as trustworthy sources of information, given their professions as physicians and their personal connections with MS. Participants felt it was left to them to do their own research about diet and MS, but preferred that the information came from MS organisations, and specifically from a health professional such as a dietitian who was knowledgeable about MS.

*Theme 3 Self-experimentation with diet to either control MS symptoms or to cure MS*

Participants who were not willing to accept the general dietary advice given primarily by the neurologist and also other health professionals (nurses) found themselves undertaking a

personal diet quest. Their intent was to alleviate symptoms such as numbness and fatigue, reverse the damage caused by MS (lesions) and/or halt their disease progression. The most extreme scenario was the hope to cure themselves of MS. Diets being followed were generally found online, and were advertised to treat or cure MS. The diet-related topics discussed in the interviews ranged from vegan, ketogenic, paleo, gluten and dairy free and a focus on vitamin D, flaxseed oil, decreased sugar and nightshades and other foods that generally were thought to cause an inflammatory response. There was a strong desire to follow the diet strictly, for fear of worsening symptoms or to optimise the potential beneficial effect of the diet. Such diets were described as expensive, and often led to social isolation due to the difficulty of maintaining the diet, especially when going out with family and friends. When the diet was particularly restrictive, the participants mentioned looking to online support groups; a reflection on the isolation caused by the strict diet.

Six participants imposed tight dietary restrictions by following special diets as a way of feeling in control of their disease. This discussion of control was sometimes intertwined with denial and a degree of self-blame. It was perceived that past diet and lifestyle habits had a causal role in the onset of MS, and a special diet was needed to control the disease. In two extreme cases, a special diet was being used as an alternative to medication, with the belief that strict adherence would aid in reversing symptoms, prevent future relapses, or reverse the damage caused by preceding relapses.

## **Discussion**

This is the first study to describe the experiences and responses to diet in people recently diagnosed with MS in Australia. The use of qualitative methodology enabled probing to explore these responses to diet and a MS diagnosis. Our results found that health professionals downplaying or not addressing the importance of following national dietary guidelines for MS was in fact having the opposite effect, with some participants seeking out information from sources that were difficult to judge credibility and changing their diet which

may lead to some serious consequences, such as refusal of medication and developing nutrient deficiencies.

Our finding that describes the perceived incompatibility of dietary advice with disease seriousness agrees with those reported by one previous study of PwMS.<sup>19</sup> The participants in that study stated they were most interested in receiving information on the scientific evidence on role of diets in MS. However, when pilot-testing the education program in that study, participants were disappointed with the lack of available scientific information as they wanted to know what the science was saying they could be doing. This is consistent with qualitative research in people with cancer, where the only dietary advice given was around a healthy, balanced diet and cancer patients also reported this was insufficient for their needs.<sup>38</sup>

Being dismissive of the limited advice given by their healthcare provider, is in line with findings by Ghafari et al in their qualitative study exploring how people adapt to having MS.<sup>39</sup> They reported that participants who were dissatisfied with the advice given by healthcare professionals were more likely to go against their recommendations. Qualitative research in PwMS from the United Kingdom found a subtheme of resistance where the patient decided to accept or reject services or treatment.<sup>40</sup> Our results indicate the worst case scenario is using alternative therapeutic diets as a disease modifying treatment (DMT)<sup>41</sup> as opposed to medication, particularly where these diets are known to result in nutrient deficiencies.<sup>42</sup>

Previous studies have also reported that a diagnosis of MS leads to information-seeking behaviour. This stems from the perceived lack of dietary information provided by healthcare professionals and wanting more disease specific dietary recommendations. What participants reported in our study was the difficulty judging the credibility of the vast amount of online information for MS, and the Internet as being the most commonly accessed source.<sup>19, 28, 43</sup> Internet sources including online forums vary in content and quality of information with reports of 27 million diet and MS related sites<sup>6</sup> with high readability.<sup>44</sup>

The concept of using diet to control and/or cure MS supports the findings of recent quantitative studies of PwMS, where up to 90% of participants reported interest in diets specifically for MS and an eagerness to adopt dietary modifications to benefit their disease.<sup>15, 19</sup> Likewise, in Australia, it has been reported that adhering to some type of alternative therapeutic diet was done with the aim of improving health, managing fatigue and other MS symptoms, and as a way of being in control and a coping strategy.<sup>21</sup> Many participants in our study were focused on symptom management whereas the current treatment strategies for MS focus on reducing disability progression of the disease using DMTs. This need in PwMS to be self-experimenting with diet as a means of being in control of an unpredictable and incurable disease has only been reported in one other general topic qualitative MS study recently,<sup>45</sup> but has been documented in other diseases such as cancer.<sup>46</sup>

We applied a number of techniques to ensure rigour,<sup>37</sup> however our findings should be interpreted with caution in light of some limitations. Firstly, the sample size was small; however, we continued data collection until we were confident that the data were saturated and the themes were representative of the range of participants' responses. Secondly, there was the potential for self-selection bias, where those who were considering diet and dietary changes may have been more likely to participate, but we attempted to control for this through limited disclosure. Finally, there was the potential for social desirability bias, although it was emphasised that all answers were participants' own experiences and opinions. Our findings were drawn from interviews of a sample of PwMS in one area of Australia. Given this context and the nature of qualitative research, the results are not generalizable beyond this, but still may have relevance to other populations in comparable settings, and are useful to inform future research.

These findings enhance our understanding about how recently diagnosed PwMS experience and respond to the dietary advice provided. Health care professionals and service providers need to fill the apparent void in this space by providing relevant and current information

about alternative therapeutic diets prompted for MS and why they are not recommended. There is also a need to improve access for PwMS to healthy diet education and for health professionals to work in a patient centre care approach using disease self-management principles so as to be able to respond to individual concerns.<sup>47</sup> Future research could build on this study to explore the dietary perceptions of PwMS for a longer period of time to investigate ongoing responses to diet and its role in MS.

### **Acknowledgements**

We would like to thank the members of MSWA for their participation, and the General Manager of Member Services, Sue Shapland, for her input in developing the interview guide.

### **Conflict of Interest**

The authors declare no conflict of interest.

**Funding:** LJB is funded by a MSWA Postdoctoral Research Fellowship. The School of Public Health XXXXXX University provided funding for this study.

## References

1. Amato MP, Derfuss T, Hemmer B, Liblau R, Montalban X, Soelberg Sorensen P *et al.* Environmental modifiable risk factors for multiple sclerosis: Report from the 2016ECTRIMS focused workshop. *Multiple sclerosis (Houndmills, Basingstoke, England)* 2017; 1352458516686847. e-pub ahead of print 2017/07/04; doi: 10.1177/1352458516686847
2. Mandia D, Ferraro OE, Nosari G, Montomoli C, Zardini E, Bergamaschi R. Environmental factors and multiple sclerosis severity: a descriptive study. *Int J Environ Res Public Health* 2014; **11**(6): 6417-6432. e-pub ahead of print 2014/06/21; doi: 10.3390/ijerph110606417
3. Reich DS, Lucchinetti CF, Calabresi PA. Multiple Sclerosis. *N Engl J Med* 2018; **378**(2): 169-180. e-pub ahead of print 2018/01/11; doi: 10.1056/NEJMra1401483
4. Browne P, Chandraratna D, Angood C, Tremlett H, Baker C, Taylor BV *et al.* Atlas of Multiple Sclerosis 2013: A growing global problem with widespread inequity. *Neurology* 2014; **83**(11): 1022-1024. e-pub ahead of print 2014/09/10; doi: 10.1212/WNL.0000000000000768
5. Palmer AJ, Colman S, O'Leary B, Taylor BV, Simmons RD. The economic impact of multiple sclerosis in Australia in 2010. *Multiple sclerosis (Houndmills, Basingstoke, England)* 2013; **19**(12): 1640-1646. e-pub ahead of print 2013/05/09; doi: 10.1177/1352458513488230
6. Farinotti M, Vacchi L, Simi S, Di Pietrantonj C, Brait L, Filippini G. Dietary interventions for multiple sclerosis. *The Cochrane database of systematic reviews* 2012; **12**: CD004192. e-pub ahead of print 2012/12/14; doi: 10.1002/14651858.CD004192.pub3
7. Bagur MJ, Murcia MA, Jimenez-Monreal AM, Tur JA, Bibiloni MM, Alonso GL *et al.* Influence of Diet in Multiple Sclerosis: A Systematic Review. *Advances in nutrition (Bethesda, Md.)* 2017; **8**(3): 463-472. doi: 10.3945/an.116.014191
8. Cunningham E. Are there evidence-based dietary interventions for multiple sclerosis? *J Acad Nutr Diet* 2013; **113**(7): 1004. e-pub ahead of print 2013/06/26; doi: 10.1016/j.jand.2013.05.010
9. Jelinek GA, Hassed CS. Managing multiple sclerosis in primary care: are we forgetting something? *Quality in Primary Care* 2009; **17**(1): 55-61.
10. von Geldern G, Mowry EM. The influence of nutritional factors on the prognosis of multiple sclerosis. *Nature reviews. Neurology* 2012; **8**(12): 678-689. e-pub ahead of print 2012/10/03; doi: 10.1038/nrneurol.2012.194



11. Maker-Clark G, Patel S. Integrative therapies for multiple sclerosis. *Disease-a-month : DM* 2013; **59**(8): 290-301. e-pub ahead of print 2013/07/24; doi: 10.1016/j.disamonth.2013.03.017
12. Riccio P, Rossano R. Nutrition facts in multiple sclerosis. *ASN Neuro* 2015; **7**(1). e-pub ahead of print 2015/02/20; doi: 10.1177/1759091414568185
13. Altowaijri G, Fryman A, Yadav V. Dietary Interventions and Multiple Sclerosis. *Current neurology and neuroscience reports* 2017; **17**(3): 28. e-pub ahead of print 2017/03/21; doi: 10.1007/s11910-017-0732-3
14. Motl RW, Mowry EM, Ehde DM, LaRocca NG, Smith KE, Costello K *et al.* Wellness and multiple sclerosis: The National MS Society establishes a Wellness Research Working Group and research priorities. *Multiple sclerosis (Houndmills, Basingstoke, England)* 2018; **24**(3): 262-267. e-pub ahead of print 2017/01/13; doi: 10.1177/1352458516687404
15. Brenton JN, Goldman MD. A study of dietary modification: Perceptions and attitudes of patients with multiple sclerosis. *Mult Scler Relat Disord* 2016; **8**: 54-57. e-pub ahead of print 2016/07/28; doi: 10.1016/j.msard.2016.04.009
16. Sui Z, Wong WK, Louie JC, Rangan A. Discretionary food and beverage consumption and its association with demographic characteristics, weight status, and fruit and vegetable intakes in Australian adults. *Public Health Nutr* 2017; **20**(2): 274-281. e-pub ahead of print 2016/08/31; doi: 10.1017/S1368980016002305
17. Grech A, Sui Z, Siu HY, Zheng M, Allman-Farinelli M, Rangan A. Socio-Demographic Determinants of Diet Quality in Australian Adults Using the Validated Healthy Eating Index for Australian Adults (HEIFA-2013). *Healthcare (Basel, Switzerland)* 2017; **5**(1). e-pub ahead of print 2017/02/07; doi: 10.3390/healthcare5010007
18. Fitzgerald KC, Tyry T, Salter A, Cofield SS, Cutter G, Fox RJ *et al.* A survey of dietary characteristics in a large population of people with multiple sclerosis. *Mult Scler Relat Disord* 2018; **22**: 12-18. e-pub ahead of print 2018/03/07; doi: 10.1016/j.msard.2018.02.019
19. Riemann-Lorenz K, Eilers M, von Geldern G, Schulz KH, Kopke S, Heesen C. Dietary Interventions in Multiple Sclerosis: Development and Pilot-Testing of an Evidence Based Patient Education Program. *PLoS One* 2016; **11**(10): e0165246. e-pub ahead of print 2016/10/21; doi: 10.1371/journal.pone.0165246
20. Schwarz S, Knorr C, Geiger H, Flachenecker P. Complementary and alternative medicine for multiple sclerosis. *Multiple sclerosis (Houndmills, Basingstoke, England)* 2008; **14**(8): 1113-1119. e-pub ahead of print 2008/07/18; doi: 10.1177/1352458508092808

21. Leong EM, Semple SJ, Angley M, Siebert W, Petkov J, McKinnon RA. Complementary and alternative medicines and dietary interventions in multiple sclerosis: what is being used in South Australia and why? *Complementary therapies in medicine* 2009; **17**(4): 216-223. e-pub ahead of print 2009/07/28; doi: 10.1016/j.ctim.2009.03.001
22. Russell R, Lucas R, Brennan V, Sherriff J, Begley A, Group TAI *et al.* Reported changes in dietary behaviour following a first clinical diagnosis of central nervous system demyelination. *Front. Neurol* 2018; **9**(161). doi: doi: 10.3389/fneur.2018.00161
23. Riccio P, Rossano R, Liuzzi GM. May diet and dietary supplements improve the wellness of multiple sclerosis patients? A molecular approach. *Autoimmune diseases* 2011; **2010**: 249842. e-pub ahead of print 2011/04/05; doi: 10.4061/2010/249842
24. Claflin SB, van der Mei IAF, Taylor BV. Complementary and alternative treatments of multiple sclerosis: a review of the evidence from 2001 to 2016. *J Neurol Neurosurg Psychiatry* 2018; **89**(1): 34-41. e-pub ahead of print 2017/08/05; doi: 10.1136/jnnp-2016-314490
25. Jelinek G. *Overcoming Multiple Sclerosis. An Evidence-Based Guide to Recovery*, Allen & Unwin: Crows Nest, NSW, 2010.
26. Wahls T, Adamson T. *The Wahls Protocol: A Radical New Way to Treat All Chronic Autoimmune Conditions Using Paleo Principles* Penguin Group: New York, USA., 2014.
27. Liamputtong P. *Qualitative research methods*, 4th edn Oxford University Press: South Melbourne, 2013.
28. Plow M, Finlayson M. A qualitative study of nutritional behaviors in adults with multiple sclerosis. *The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses* 2012; **44**(6): 337-350. e-pub ahead of print 2012/11/06; doi: 10.1097/JNN.0b013e3182682f9b
29. Kilborn SJ. Dietary assessment and self-perceived impact of food in persons with multiple sclerosis. (Master's thesis) Master's thesis, McGill University, Montreal, 2008.
30. Wu YP, Yi J, McClellan J, Kim J, Tian T, Grahmann B *et al.* Barriers and facilitators of healthy diet and exercise among adolescent and young adult cancer survivors: Implications for behavioral interventions. *Journal of Adolescent and Young Adult Oncology* 2015; **4**(4): 184-191. doi: 10.1089/jayao.2015.0028
31. Brownie S, Coutts R. Older Australians' perceptions and practices in relation to a healthy diet for old age: a qualitative study. *J Nutr Health Aging* 2013; **17**(2): 125-129. e-pub ahead of print 2013/02/01; doi: 10.1007/s12603-012-0371-y

32. Lucan SC, Barg FK, Karasz A, Palmer CS, Long JA. Concepts of healthy diet among urban, low-income, African Americans. *Journal of community health* 2012; **37**(4): 754-762. e-pub ahead of print 2011/11/22; doi: 10.1007/s10900-011-9508-x
33. Corbin J, Strauss A. *Basics of qualitative research: Techniques and procedures for developing grounded theory*, 3rd edn Sage Publications: California, 2008.
34. Charmaz K. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*, SAGE Publications: London, 2006.
35. Conrad P, Barker KK. The social construction of illness: key insights and policy implications. *J Health Soc Behav* 2010; **51 Suppl**(5): S67-79. e-pub ahead of print 2010/12/22; doi: 10.1177/0022146510383495
36. Kerr A, Ross E, Jacques G, Cunningham-Burley S. The sociology of cancer: a decade of research. *Sociol Health Illn* 2018; **40**(3): 552-576. e-pub ahead of print 2018/02/16; doi: 10.1111/1467-9566.12662
37. Denzin N, K., Lincoln YS. *The Sage Handbook of Qualitative Research*, Sage: Thousand Oaks, California, 2011.
38. James-Martin G, Koczwara B, Smith EL, Miller MD. Information needs of cancer patients and survivors regarding diet, exercise and weight management: A qualitative study. *European Journal of Cancer Care* 2014; **23**(3): 340-348. doi: 10.1111/ecc.12159
39. Ghafari S, Fallahi-Khoshknab M, Nourozi K, Mohammadi E. Patients' experiences of adapting to multiple sclerosis: a qualitative study. *Contemp Nurse* 2015; **50**(1): 36-49. e-pub ahead of print 2015/07/28; doi: 10.1080/10376178.2015.1010252
40. Methley AM, Chew-Graham CA, Cheraghi-Sohi S, Campbell SM. A qualitative study of patient and professional perspectives of healthcare services for multiple sclerosis: implications for service development and policy. *Health & social care in the community* 2017; **25**(3): 848-857. e-pub ahead of print 2016/07/12; doi: 10.1111/hsc.12369
41. Ceuninck van Capelle A, Meide HV, Vosman FJH, Visser LH. A qualitative study assessing patient perspectives in the process of decision-making on disease modifying therapies (DMT's) in multiple sclerosis (MS). *PLoS One* 2017; **12**(8): e0182806. e-pub ahead of print 2017/08/25; doi: 10.1371/journal.pone.0182806
42. Masullo L, Papas MA, Cotugna N, Baker S, Mahoney L, Trabulsi J. Complementary and alternative medicine use and nutrient intake among individuals with multiple sclerosis in the United States. *Journal of community health* 2015; **40**(1): 153-160. e-pub ahead of print 2014/07/02; doi: 10.1007/s10900-014-9913-z

43. Beckett JM, Bird ML, Pittaway J, Ahuja KD. Online dietary advice for the symptomatic management of multiple sclerosis: a scoping review protocol. *JBI database of systematic reviews and implementation reports* 2017; **15**(2): 230-235. e-pub ahead of print 2017/02/09; doi: 10.11124/jbisrir-2016-002937
44. Moccia M, Carotenuto A, Massarelli M, Lanzillo R, Brescia Morra V. Can people with multiple sclerosis actually understand what they read in the Internet age? *Journal of clinical neuroscience : official journal of the Neurosurgical Society of Australasia* 2016; **25**: 167-168. e-pub ahead of print 2015/11/04; doi: 10.1016/j.jocn.2015.10.003
45. Plow MA, Golding M. A Qualitative Study of Multiple Health Behaviors in Adults with Multiple Sclerosis. *International journal of MS care* 2016; **18**(5): 248-256. e-pub ahead of print 2016/11/03; doi: 10.7224/1537-2073.2015-065
46. Maley M, Warren BS, Devine CM. A second chance: meanings of body weight, diet, and physical activity to women who have experienced cancer. *Journal of nutrition education and behavior* 2013; **45**(3): 232-239. e-pub ahead of print 2013/02/12; doi: 10.1016/j.jneb.2012.10.009
47. Members of the MSitsCSG, Rieckmann P, Centonze D, Elovaara I, Giovannoni G, Havrdova E *et al.* Unmet needs, burden of treatment, and patient engagement in multiple sclerosis: A combined perspective from the MS in the 21st Century Steering Group. *Mult Scler Relat Disord* 2018; **19**: 153-160. e-pub ahead of print 2017/12/15; doi: 10.1016/j.msard.2017.11.013