

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

Running title: Dietary attitudes and multiple sclerosis

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1 **Abstract**

2 **Background/Objectives:**

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

9 **Subjects/Methods:**

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

13 **Results:**

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

18 **Conclusions:**

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

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

28 **Introduction**

29 Multiple sclerosis (MS) is an immune-mediated disease characterised by the inflammatory
30 damage and formation of scars on the myelin sheaths of the central nervous system axons.¹
31 The destruction of neurons and subsequent sclerosis can result in a wide range of
32 symptoms due to the disturbance of neurological signal transmission, including cognitive
33 decline, blurred vision, speech impairment, muscle weakness and tremors, bladder and
34 bowel dysfunction, and fatigue.² The most common form of MS is the relapsing-remitting
35 form, where people with MS (PwMS) have episodic relapses in which a sudden onset or
36 increase in symptoms occurs. This makes the disease unpredictable. The cause of MS
37 remains unknown and there is no known cure; however medication is used to manage
38 disease progression. MS is one of the most common causes of neurological disability in
39 young adults worldwide, second only to traumatic brain injury.³ The disease affects at least
40 2.3 million people globally⁴ and the prevalence in Australia is estimated to be 95.2 per 100
41 000.⁵ The most frequent age of onset is between 20 and 40 years and, in Australia, women
42 are three times more likely to have the disease than men.⁵

43 Several reviews have examined the role of diet therapy on the management of MS
44 symptoms and disease progression including two systematic reviews^{6, 7} and several scoping
45 or short reviews.⁸⁻¹⁴ Evidence for a therapeutic diet for MS is insufficient and dietary advice
46 for PwMS is to consume a healthy diet in line with national dietary guidelines.⁷ The aims of
47 this advice is to improve the wellbeing and sense of control in PwMS.¹⁵ It is estimated that
48 up to 42% of adults across the United States,^{15, 16} Germany,^{17, 18} and Australia^{19, 20} report
49 making dietary changes after being diagnosed with MS, however these changes are not
50 always in line with recommendations and little is known about the reasons for change.
51 There are alternative therapeutic diets who purport to modulate the inflammatory response
52 of the disease²¹ and a range of complementary and alternative medicine (CAM) uses
53 documented in PwMS.²² Alternative therapeutic diets such as those promoted by Jelinek²³

54 and Wahls²⁴ in addition to CAMs are being promoted for PwMS with no or limited evidence
55 of efficacy.⁷

56 Qualitative research assists in our understanding of people's experiences and behaviours
57 with disease and the meanings that people ascribe to these experiences and behaviours in
58 the context of their everyday lives and social environments.²⁵ There is limited research on
59 the reasons for making dietary changes in PwMS and to our knowledge, only one published
60 qualitative study has explored the impact of MS on dietary behaviours,²⁶ however the study
61 suffered from a number of rigour issues.²⁵

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

69 **Materials and Methods**

70 **Study design**

71 Due to the lack of previous research in this area, we used a qualitative methodology, guided
72 by grounded theory principles. Grounded theory is useful when no prior theory about
73 behaviours exists and researchers aim to broadly inductively develop a general
74 explanation.²⁵ In this study the focus was on the experiences and responses (attitudes,
75 beliefs and actions) related to diet after an MS diagnosis.

76 **Participants and recruitment**

77 Purposive sampling was undertaken with potential participants contacted through a non-
78 profit MS organisation, Multiple Sclerosis Society of Western Australia (MSWA). MSWA is a
79 primary service and support provider for people with neurological conditions living in WA and

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

95

96 **Data collection**

97 Individual interviews were chosen to enable in-depth exploration of each person's MS
98 experience and how they made sense of diet in response to MS. An interview guide (Table
99 1) was developed with input from the research team (two nutritionists and two dietitians) and
100 the General Manager of Member Services at MSWA. Questions from other qualitative
101 studies were reviewed including a) two studies (one published and one higher degree)
102 exploring dietary behaviours of individuals with MS,^{26, 27} b) dietary perceptions from people
103 with cancer,²⁸ and c) general barriers and facilitators to a healthy diet for adults.^{29, 30} In order
104 to assess the interview duration and feasibility of the interview guide, the first author (RR)
105 piloted the interview guide on two PwMS whose data were not included in the analysis.

106 Interviewing techniques and the guide were then revised under the guidance of an
107 experienced qualitative researcher (AB).

108 Insert Table 1 Interview guide

109 The interviews took place in a private meeting room at the MSWA facilities in 2017 by the
110 first author (RR) or by videoconference using the Internet software application Skype for
111 participants unable to travel (version 7.58, Microsoft Corp., Luxembourg). Probing was used
112 to elicit further information as required. All interviews were digitally recorded and transcribed
113 verbatim within 24 hours of interview completion, and memos were written reflecting on data
114 analysis processes in response to emerging codes as part of a reflexive process. Member
115 checking was used where participants could have their transcripts posted to them to ensure
116 the data were accurately transcribed, and satisfactorily reflected their views and opinions.
117 The recruitment, data collection and analysis process continued until data saturation, where
118 no new relevant knowledge was reached.²⁵ The average interview time was 54 minutes.

119

120 **Data analysis**

121 Data were analysed using a grounded theory approach, where analysis commenced after
122 the first interview in an iterative process using a constant comparative technique.³¹ NVivo
123 software (version 11.4.0, QSR International Pty Ltd) facilitated data organisation. The
124 transcripts were examined line-by-line by the interviewer (RR) to identify words, phrases,
125 and states of mind of significance to generate initial codes in an open coding process. Both
126 literal and interpretive coding was undertaken, referring to coding direct observations from the
127 data, and what was inferred from the data, respectively.³¹ After theoretical saturation was
128 reached on the completion of open-coding, we conducted a brief literature review on diet
129 and other chronic diseases, as recommended by Charmaz.³² As the analysis progressed,
130 the theoretical perspective of social constructivism was applied to the emerging themes,
131 where illness is constructed through the understanding of social realities resulting in multiple

132 realities about the meaning of a disease and impact on everyday life.³³ Expert medical
133 knowledge can influence patients' behaviours and their experiences with how they construct
134 meaning of their illness, particularly in creating lay knowledge and explanations.³⁴ The initial
135 codes were grouped into categories and subcategories based on similarities and
136 differences, then narrowed down and organised into themes. Peer debriefing was used to
137 confirm the emerging themes by an experienced qualitative researcher (AB) and then
138 broadly discussed with the research team in a number of meetings focused on emerging
139 codes and questions to be explored in successive interviews.³⁵ Discrepancies in coding
140 were discussed and resolved by returning to the data. The final themes were discussed with
141 the General Manager of MSWA who was independent to the research to assess their
142 confirmability.

143

144 **Results**

145 **Participants' characteristics**

146 Eleven PwMS, two men and nine women participated in this study. Participants had been
147 diagnosed with MS for an average of eight months (range 3-15 months), and their average
148 age was 47 years (range 31-70 years). Most participants were married (73%) and employed
149 (91%). Table 2 presents the self-reported characteristics of the participants.

150

151 Insert Table 2

152

153 **Themes**

154 Three key themes emerged from the analysis as responses specific to diet in PwMS. Firstly,
155 there was a perceived incompatibility of the lack of/or generalised dietary advice considering
156 disease seriousness at the time of diagnosis, secondly, extensive personal research and
157 information seeking with difficulty judging credibility and the final theme was one of self-

158 experimentation with diet to either control MS symptoms or cure MS. Excerpts from
159 interviews are presented in Table 3, with pseudonym and time since diagnosis after each
160 quote.

161 Insert Table 3

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

164 All participants recalled that at the time of their diagnosis, there was very little discussion
165 about what they should do about diet. If general dietary advice was provided by the
166 neurologist, it was perceived as vague and not specific enough to MS. Participants were
167 frustrated by this lack of specific dietary advice, particularly given the seriousness and
168 incurability of their disease diagnosis. Participants either accepted they needed to follow
169 national dietary guidelines if this was discussed or were dismissive of this advice. The
170 former trusted that their neurologist or MSWA would provide information regarding dietary
171 changes that might help their MS, and didn't question further. Participants who dismissed
172 perceived scant dietary advice such as 'be aware of it' assumed the lack of information
173 reflected a lack of knowledge about the link between diet and MS by health professionals.
174 They were convinced there had to be something more to the diet story, however participants
175 had difficulty articulating what a healthy diet actually was.

176

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

179 Not receiving enough dietary advice at diagnosis led most participants to search for their
180 own information. Participants referred to a wide range of sources, including the Internet,
181 friends, family, other PwMS, chiropractors and naturopaths, but rarely mentioned MS
182 organisations or dietitians. The internet opened up a multitude of alternative diets and foods
183 for MS including those promoted by doctors (Jelinek, Wahls) this contributed to the

184 frustration that their disease wasn't being taken seriously by people and organisations they
185 felt should be able to provide more specific dietary advice.

186

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

196

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

198 Participants who were not willing to accept the general dietary advice given primarily by the
199 neurologist and also other health professionals (nurses) found themselves undertaking a
200 personal diet quest. Their intent was to alleviate symptoms such as numbness and fatigue,
201 reverse the damage caused by MS (lesions) and/or halt their disease progression. The
202 most concerning scenario was the hope to cure themselves of MS. Diets being followed
203 were generally found online, and were advertised to treat or cure MS. The diet-related
204 topics discussed in the interviews ranged from vegan, ketogenic, paleo, gluten and dairy free
205 and a focus on vitamin D, flaxseed oil, decreased sugar and nightshades and other foods
206 that generally were thought to cause an inflammatory response. There was a strong desire
207 to follow the diet strictly, for fear of worsening symptoms or to optimise the potential
208 beneficial effect of the diet. Such diets were described as expensive, and often led to social
209 isolation due to the difficulty of maintaining the diet, especially when going out with family

210 and friends. When the diet was particularly restrictive, the participants mentioned looking to
211 online support groups; a reflection on the isolation caused by the strict diet.

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

219 **Discussion**

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

227 Our finding that describes the perceived incompatibility of dietary advice with disease
228 seriousness agrees with those reported by one previous study of PwMS.¹⁷ The participants
229 in that study stated they were most interested in receiving information on the scientific
230 evidence on role of diets in MS. However, when pilot-testing the education program in that
231 study, participants were disappointed with the lack of available scientific information as they
232 wanted to know what the science was saying they could be doing. This is consistent with
233 qualitative research in people with cancer, where the only dietary advice given was around a
234 healthy, balanced diet and cancer patients also reported this was insufficient for their
235 needs.³⁶

236 Being dismissive of the limited advice given by their healthcare provider, is in line with
237 findings by Ghafari et al in their qualitative study exploring how people adapt to having MS.³⁷
238 They reported that participants who were dissatisfied with the advice given by healthcare
239 professionals were more likely to go against their recommendations. Qualitative research in
240 PwMS from the United Kingdom found a subtheme of resistance where the patient decided
241 to accept or reject services or treatment.³⁸ Our results indicate the worst case scenario is
242 using alternative therapeutic diets as a disease modifying treatment (DMT)³⁹ as opposed to
243 medication, particularly where these diets are known to result in nutrient deficiencies.⁴⁰

244 Previous studies have also reported that a diagnosis of MS leads to information-seeking
245 behaviour. This stems from the perceived lack of dietary information provided by healthcare
246 professionals and wanting more disease specific dietary recommendations. What
247 participants reported in our study was the difficulty judging the credibility of the vast amount
248 of online information for MS, and the Internet has been being the most commonly accessed
249 source.^{17, 26, 41} Internet sources including online forums vary in content and quality of
250 information with reports of 27 million MS related sites with high readability.⁴²

251 The concept of using diet to control and/or cure MS supports the findings of recent
252 quantitative studies of PwMS, where up to 90% of participants reported interest in diets
253 specifically for MS and an eagerness to adopt dietary modifications to benefit their
254 disease.^{15, 17} Likewise, in Australia, it has been reported that adhering to some type of
255 alternative therapeutic diet was done with the aim of improving health, managing fatigue and
256 other MS symptoms, and as a way of being in control and a coping strategy.¹⁹ Many
257 participants in our study were focused on symptom management whereas the current
258 treatment strategies for MS focus on reducing disability progression of the disease using
259 DMTs. This need in PwMS to be self-experimenting with diet as a means of being in control
260 of an unpredictable and incurable disease has only been reported in one other general topic
261 qualitative MS study recently,⁴³ but has been documented in other diseases such as
262 cancer.⁴⁴

263 We applied a number of techniques to ensure rigour,³⁵ however our findings should be
264 interpreted with caution in light of some limitations. Firstly, the sample size was small;
265 however, we continued data collection until we were confident that the data were saturated
266 and the themes were representative of the range of participants' responses. Secondly, there
267 was the potential for self-selection bias, where those who were considering diet and dietary
268 changes may have been more likely to participate, but we attempted to control for this
269 through limited disclosure. Finally, there was the potential for social desirability bias,
270 although it was emphasised that all answers were participants' own experiences and
271 opinions. Our findings were drawn from interviews of a sample of PwMS in one area of
272 Australia. Given this context and the nature of qualitative research, the results are not
273 generalizable beyond this, but still may have relevance to others populations in comparable
274 settings, and are useful to inform future research.

275 These findings enhance our understanding about how recently diagnosed PwMS experience
276 and respond to the dietary advice provided. Health care professionals and service providers
277 need to fill the apparent void in this space by providing relevant and current information
278 about alternative therapeutic diets prompted for MS and why they are not recommended.
279 There is also a need to improve access for PwMS to healthy diet education and for health
280 professionals to work in a patient centre care approach using disease self-management
281 principles so as to be able to respond to individual concerns.⁴⁵ Future research could build
282 on this study to explore the dietary perceptions of PwMS for a longer period of time to
283 investigate ongoing responses to diet and its role in MS.

284

285 **Acknowledgements**

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

288

289 **Conflict of Interest**

290 The authors declare no conflict of interest.

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

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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"> ○ How do you know if a dietary pattern you're following works for you? ○ Can you tell me about of any diets for MS you've heard about? <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? [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>

Table 2 Participant characteristics (*n*=11)

Participant characteristics		
Interview duration (minutes)		54 (range 23-78)
Sex <i>n</i> (%)		
	Male	2 (18%)
	Female	9 (82%)
Age (years) mean \pm SD		47 \pm 13
Country of birth <i>n</i> (%)		
	Australia	7 (64%)
	Other	4 (36%)
Marital status <i>n</i> (%)		
	Married	8 (73%)
	Other	3 (27%)
Living arrangements <i>n</i> (%)		
	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%)

SD: standard deviation; MS: multiple sclerosis.

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

<p><i>Perceived incompatibility of lack of/or generalised dietary advice with disease seriousness</i></p> <p>“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)</p> <p>“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)</p> <p>“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)</p> <p>“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)</p> <p>“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)</p>
<p><i>Diagnosis-driven extensive information-seeking behaviour</i></p> <p>I have this overwhelming need to search everything (Deb, 12 months since diagnosis)</p> <p>I've done a lot of research actually into what I should and shouldn't be eating (Donna, 4 months since diagnosis)</p> <p>“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)</p>
<p><i>Self-experimentation with diet to either control MS symptoms or to cure MS</i></p> <p>I think for me, um, I'd doing this as a self-discovery journey (Alicia, 4 months since diagnosis)</p> <p>I generally think to try things I've got nothing to lose (Deb, 12 months since diagnosis)</p> <p>“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)</p> <p>“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)</p>