1 Original Research: Multiple Sclerosis and Related Disorders 2 MSARD-D-20-00544 3 The unresolved role of the neurologist in providing dietary 4 advice to people with multiple sclerosis 5 6 R. D. Russella, L. J. Blacka, A. Begleya 7 8 Affiliations: 9 <sup>a</sup>School of Public Health, Curtin University, Perth, Australia 10 11 12 **Corresponding Author:** 13 Andrea Begley 14 School of Public Health, Kent St, Bentley WA 6102 15 a.begley@curtin.edu.au 16 +61 8 9266 2773 17 **Highlights** 18 19 Dietary advice provided to patients ranged from none to counselling about specific 20 21 Neurologists felt they had little influence over their patients' dietary habits Neurologists could direct patients to evidence-based resources (national dietary 22 23 quidelines) 24 **Abstract** 25 26 Background: People with MS often make dietary changes after diagnosis with the aim of 27 slowing disease progression. Although people with MS commonly use the internet for 28 information on diet and MS, neurologists are their preferred source of information. However, 29 little is known about what dietary advice is provided by neurologists. 30 **Objectives:** To explore the perceptions of neurologists about diet and MS, and to identify

the type of dietary advice they provide to their patients with MS.

Methods: In this exploratory qualitative study, 11 semi-structured interviews were conducted with neurologists in Western Australia. Audio files were transcribed verbatim, and transcripts were thematically analysed using a general inductive approach.

**Results:** Four themes emerged: 1) juggling the evidence on the role of diet in MS; 2) acknowledging the risks and benefits of specific diets; 3) distancing from the diet 'gurus'; and 4) the unresolved role of the neurologist in providing dietary advice.

**Conclusion:** Neurologists could meet their patients' expectations by providing evidence-based dietary advice, such as promoting the benefits of diets that adhere to national dietary guidelines, and being prepared to explain potential risks of restrictive diets. Information about healthy eating needs to be targeted to people with MS.

**Keywords:** Diet; dietary advice; dietary guidelines; multiple sclerosis; nutrition; neurologists

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### 1. Introduction

Despite the lack of scientific evidence for any therapeutic diet(1), approximately 40% of people with MS (pwMS) report making dietary modifications after being diagnosed(2-4), often with the aim of slowing disease progression(5). For pwMS, the internet is the most common source of information on diet(6, 7), where a number of specific diets are promoted. Many of these diets are restrictive, i.e. they do not satisfy the minimum nutrient requirements according to national dietary guidelines. A recent scoping review highlighted the wide range of non-evidenced-based online dietary advice promoted for pwMS, much of which was contradictory(7). Popular restrictive diets vary markedly in composition and include the Swank Diet (saturated fat restricted to <15 g/day; unsaturated fat restricted to <20-50 g/day; limited red meat)(8), the Overcoming MS Recovery Program (low in saturated fat; moderate in seafood, avocado and nuts; no meat, dairy, egg yolks, or refined foods)(9), and the Paleo diet (high in meat, vegetables, and fruits; no dairy, legumes, eggs, or grains)(1). PwMS find it

difficult to judge the credibility of online dietary information, but generally trust professionals with reputable titles, such as doctors (even when the diets are not evidence-based)(5). Although the internet is commonly used for information on diet, neurologists are the preferred and most trusted source of health information for pwMS(10, 11) and, therefore, should be prepared to offer evidence-based dietary advice, and/or refer to a dietitian where required.

In Australia, people newly diagnosed with MS have reported that their neurologist provided either no information, or very little information, about diet(5). When dietary advice was provided, it was likely to be general and not tailored to MS(5); however, pwMS consider generic health information to be of little use(12). PwMS want neurologists to proactively provide information about all aspects of the disease(13), since accurate information can help with decision-making and self-management of the disease(14). Given that little is known about the dietary advice provided by neurologists to pwMS, we aimed to explore the perceptions of neurologists about diet and MS, and to identify the type of dietary advice they provide to their patients with MS.

# 2. Methods

We conducted an exploratory qualitative study, with methods guided by a general inductive approach (where raw data was used to derive themes)(15). The study was conducted in Perth, Western Australia (WA), between June 2019 and March 2020, and was approved by the Human Research Ethics Committee at Curtin University (approval number HRE2019-0179). Prior to commencing interviews, participants were given written study information (containing information on the expected duration, study aims, and anonymity) and provided written, informed consent. We adhered to the Standards for Reporting Qualitative Research (SRQR)(16).

# 2.1 Participant recruitment

We estimated that there were 40-50 neurologists working in WA at the time of recruitment(17). Neurologists who were diagnosing and/or treating pwMS in WA were eligible. There were no exclusion criteria. We used purposive and snowball sampling methods(18). After discussions with MS Western Australia (MSWA) and the project stakeholder advisory group, we created an initial list of potential participants from both public

and private health sectors. Additional participants were identified by using an online search engine (Google), and participants were asked at the conclusion of the interview for names of other neurologists to contact. Neurologists were contacted by email or phone, and invited to participate in a single interview. We encouraged neurologists to participate even if they provided little or no dietary advice to their MS patients.

### 2.2 Data collection

The interview topic guide (Table 1) was developed with input from both the research team and from relevant literature(19, 20). Given the time constraints for the neurologists, we aimed to complete the interviews within 30 minutes. Two authors (R.D.R., nutritionist and PhD student, and A.B., dietitian and qualitative researcher) piloted the topic guide with one neurologist for interview duration and suitability of the questions. The topic guide was not altered after piloting; hence, the transcript of the pilot interview was included in the analysis. At the beginning of the interviews, the study aims were discussed and demographic information was collected using a short questionnaire. Interviews were audio-recorded, transcribed verbatim, and rechecked for accuracy by R.D.R. The interviewer (R.D.R.) made notes after each interview, outlining emotional responses, key phrases, and topics to probe in subsequent interviews. For reflexivity(18), R.D.R. reflected on her assumptions. To ensure that comments reflected the practices and opinions of the neurologists, transcripts were posted to participants for member checking(18). No amended transcripts were returned. Recruitment continued until thematic saturation was reached (i.e. no new themes emerged from the data)(21).

Table 1 Interview topic guide

Topics	Discussion guide
Diets for MS	In your clinical experience, what is your take on the role of diet and MS? (Probe: to elaborate further; why/why not?) Can you tell me about any diets that you have heard about or read about for MS? There are some people with medical training, including in neurology, that promote specific diets for MS. What are your views on that?
Provision of dietary advice and information	When you are diagnosing a patient with MS, what emphasis do you place on diet; where does dietary information sit? Is there anything you routinely discuss about diet with your patients? (Probe why/why not?) How often would you say that your patients have questions for you about diet?

- What (if anything) do they typically ask of you?
   What information do you provide about diet, and why? (If none, then why not?)
  - Are there any resources you give out, or direct patients to?
  - What [additional] resources would you like to be able to refer client to? I.e. where should your patients get nutrition information from?
- If a patient were to come to you, and insist on following a specific diet for their MS, and choosing to do a diet over taking medication, how would you typically respond to that? (Follow-up: how would you respond if that patient agreed to take the recommended medication, but was still insistent on following the specific diet?)
  - What do you perceive to be some of the benefits to them following a specific diet if they are continuing to take their recommended medication?
  - What do you perceive to be some of the risks to them following a specific diet if they are continuing to take their recommended medication?

As their neurologist, what degree of influence do you think you have on your patients' dietary habits if you were to make suggestions or recommendations?

Conclusion

Anything else you would like to add that I have not covered?

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### 2.3 Analysis

Commencing after the first interview, the interviewer (R.D.R.) used inductive thematic analysis methods(15) to analyse the transcripts. The transcripts were read in detail to identify sections of text that related to the objectives, creating 39 categories in the initial coding stage. We used literal (direct observations from the data) and interpretive (inferred from the data) coding techniques(22). For the second stage of coding, categories were reduced and refined by grouping those with similar meanings, resulting in 15 categories.

129 Final revision involved reducing redundant categories and creating relevant subcategories.

This resulted in four overarching themes.

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The research team discussed emerging themes throughout the analysis process as a means of peer debriefing(18). This encouraged new perspectives from those who were external to the data collection and not immersed in the data, ensuring credibility of the findings. A.B. (an experienced qualitative researcher) listened to all audio recordings, and L.J.B. acted as an external auditor (was not involved in data collection or preliminary analysis). Final themes were confirmed by the research team. NVivo software (version 12.6.0, QSR International Pty

Ltd) was used for qualitative data management. Stata software (version 16.0, StataCorp LP, College Station, TX, USA) was used to analyse participant characteristics.

# 3. Results

# 3.1 Participants

We interviewed 11 neurologists: eight interviews were conducted in person and three were conducted using Skype (version 7.58, Microsoft Corp., Luxembourg). The mean interview duration was 26 minutes (range, 18-42 minutes). Participant characteristics are presented in Table 2. The majority were male (64%), with equal representation across the public and private sectors (36% public; 36% private; 27% a combination of both). The median number of years since qualifying was 12 years (range, 8-27 years). The proportion of pwMS treated by neurologists in the previous three working days ranged from zero to 50% (median, 5%).

**Table 2** Characteristics of the participants

(1)	
Sex, n (%)	
Male	7 (63.6%)
Female	<i>4</i> (36.4%)
Health sector, n (%)	
Public	<i>4</i> (36.4%)
Private	<i>4</i> (36.4%)
Both	3 (27.3%)
Location of practice	
Perth <sup>1</sup> metropolitan only	6 (54.5%)
Perth <sup>1</sup> metropolitan and regional Western Australia	<i>5</i> (45.5%)
Country of medical training <sup>2</sup> , n (%)	
Australia	9 (81.8%)
Other	6 (54.5%)

	Number of years practicing medicine		
	Median (IQR, range)	22 (14, 19-38)	
	Number of years as a qualified neurologist	40 (40 0 07)	
	Median (IQR, range)  Percentage of MS patients seen in previous three	12 (13, 8-27)	
	working days		
	Median (range)	5% (0-50%)	
159	IQR, interquartile range		
160 161	<sup>1</sup> Capital city of Western Australia <sup>2</sup> Participants could record multiple countries		
101	r ditiolpanto codia roccia matapio coditirios		
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163	3.2 Themes		
164	Inductive thematic analysis resulted in four overarching the	emes: 1) juggling the	e evidence on
165	the role of diet in MS; 2) acknowledging the risks and bene	, , , , ,	
166	from the diet 'gurus'; and 4) the unresolved role of the neu	•	,
167	Quotes to support themes are presented in Table 3.	3 1 3	,
	accesses to supplies manner and processing in the supplies		
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169	3.2.1 Theme 1 Juggling the evidence on the role of	f diet in MS	
170	In most cases, the dietary advice given by neurologists to	pwMS was informed	d by credible
171	sources, such as peer-reviewed journals, MS conferences	, and dietitians. Hov	vever, when
172	healthy eating was mentioned, the descriptions were vagu	e; "I just tell them to	eat well" (N7),
173	and there was no reference to an evidence-based resource	e, such as the <i>Austi</i>	ralian Dietary
174	Guidelines. The advice was inconsistent with no apparent	clinical consensus.	Some
175	neurologists relied on anecdotes from other patients, or on	their own personal	food
176	preferences, to inform the dietary advice they provided.		
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178	The viewpoints of the neurologists on the role of diet range	ed from sceptics (did	d not see a role
179	for diet in general) through to those who counselled patien	ts with information a	about specific
180	diets (e.g. Mediterranean, vegan, or the Overcoming MS R	Recovery Program d	iet). Some
181	neurologists were "deliberately vague" (N1) when giving di	etary advice. Reaso	ons for
182	providing little or no dietary advice included limited knowle	dge about diet/nutri	tion or being
183	unsure what the right advice was, given the lack of evidence	_	_
184	more robust evidence in the field of diet and MS before the	<b>G</b>	
185	make any dietary recommendations or to counsel for/agair		•
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Neurologists who emphasised the importance of diet cited general health, weight

187 management, vascular health, and a sense of wellbeing, as reasons for giving dietary 188 advice. 189 190 There was very little discussion on the role of diet in managing the symptoms of MS, and 191 any such discussion was limited to the symptoms of constipation and fatigue. A few 192 neurologists avoided discussing diet if their patients indicated they were already following a 193 restrictive diet. Contradicting patients with information that the diet was not evidence-based 194 was considered confronting, and was avoided. Rarely, neurologists were openly supportive 195 of their patients trying specific diets, and spent time helping them make an informed choice. 196 197 198 199 200 201 202 203 204 205 206 207 **Table 3** Participant quotes to support themes Theme 1 Juggling the evidence on the role of diet in MS

"I might say, 'You know, I've had some patients actually come off treatment and done really well on that [particular diet]'." N3

"Until there is some concrete evidence about [a] specific diet, um, I, I would, I'd be a sceptic." N5

"A lot of people do go on to specific diets and they ask me, you know, what I recommend. And I'm deliberately vague, because I don't really know for sure. There's not enough evidence to be confident of what diet is, is appropriate." N1

"[When] the patients come to me, I never really give them much information on diet. I just tell them to eat well." N7

"People don't like to be contradicted. So if someone thinks a low-fat diet will cure my MS, there's no point in me saying that's a pile of crap." N10

"I'd have to look at the diet, see what's known about the diet, and then discuss it with the patient. So I am, I am open minded to this." N4

"General cardiovascular health, general cerebrovascular health, [...] not being overweight, ah, just general health issues. Which actually translates into a good immune system, and looking after yourself." N2

"If I think they're very limiting, so some go on like a vegan one, ah, I just ensure that they get all the vitamins. I prescribe them multivitamins or get them to buy them." N8

"Suddenly someone who can't touch or eat anything at anyone's place, you're changing how you present to your friends, to your family, to your children. Ah, and I think that's a problem. You want a diet that integrates with society." N2

"'Well must be your fault. It must be that you didn't stick to the diet'. Which can become damaging for peoples ah, you know, mental health, if they think the MS getting worse is their fault." N11

"Yeah, I mean, the thing with neurological conditions, including MS is, things feel like they're out of control OK. You're losing control of your limb or your vision or whatever. So, so sometimes diet is a form of control." N8

"Some patients that are overweight with MS can, can lose weight on those diets, and obesity is a risk factor for um, poor prognosis in MS." N11

### Theme 3 Distancing from the diet 'gurus'

"[People] strongly believe what they're told by, you know, by certain, you know Terry Wahls¹ or George Jelinek² because they are very, you know, they're very sort of um, concrete. And 'this is this is right, and correct', and people like that certainty." N1

"It all has to be science-based. It can't be religion-based, it can't be faith-based. You know, we've got to collect evidence, find the evidence." N10

"I think it's very common for people to be caught up in the zeitgeist, and be, 'Okay, I'm gonna go vegan, dairy-free, gluten-free', even though they don't have intolerance to those things." N1

"Dr Terry Wahls in North America, same idea, slightly guru paradigm, someone comes along and says I've got MS and I eat bananas, and you know, cured MS." N10

#### Theme 4 The unresolved role of the neurologist in providing dietary advice

"I don't know that I have that much influence over what people do in terms of their diet." N11

"Usually unless they ask directly about it [diet], I don't address it. There's just not enough time in the day." N9

"They might have the intent to stick to a very restrictive diet, but mostly they can't [...] they self-protect in a way." N8

"Honestly, I would wait for the patient to bring it up, um, except for vitamin D, I don't bring up anything else about diet." N5

"[If] it gets to a point where I think that they need like really good dietary advice, I will send them to a dietitian." N4

"[If patients ask] whether any particular type of diet would be helpful or not [...] my usual suggestion is that you can try that and you can see if it works." N5

- 208 N[x], neurologist ID code
- 209 <sup>1</sup>Dr Wahls promotes the Wahls Paleo Protocol
- 210 <sup>2</sup>Professor Jelinek promotes the Overcoming MS Recovery Program

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#### 3.2.2 Theme 2 Acknowledging the risks and benefits of specific diets

- 213 Nutrient deficiencies and unintended weight loss were the most commonly mentioned risks
- 214 associated with specific diets, although probing was needed to extract this topic of
- discussion. For patients where nutrient deficiencies were a concern, half of the neurologists
- said they would recommend a dietary supplement. Patients who were committed to following

217 218 219 220 221 222	a restrictive diet were rarely referred to a dietitian. Only one neurologist mentioned ordering blood tests to ensure their patients on restrictive diets were not suffering from nutrient deficiencies. Any potential deleterious effects on mental health were rarely discussed. A few neurologists considered restrictive diets to be socially isolating, and two discussed the guilt felt by pwMS if they strayed from the diet. Those neurologists noted that patients often blamed their relapses on poor adherence to their chosen diet.
<ul><li>223</li><li>224</li><li>225</li><li>226</li><li>227</li><li>228</li><li>229</li></ul>	Most neurologists acknowledged that certain diets could be beneficial, including low-fat, Mediterranean, vegan, and restrictive (e.g. Paleo) diets, as they were likely to be healthier than the patient's previous diet. Commonly cited benefits of such diets included increased energy levels, improved heart and/or brain health, weight loss, having a sense of control, and generally feeling better.
230 231 232 233 234 235 236	3.2.3 Theme 3 Distancing from the diet 'gurus' Given the lack of evidence for altering the disease course, most neurologists were dismissive of the restrictive diets. However, they thought that their patients considered the dietary advice from the "gurus" (N10) as clear, concise, and trustworthy. The language used when referring to restrictive diets and their promotors was distancing and dismissive, with references to pwMS having faith and belief in the 'gurus'.
237 238 239 240 241	The neurologists were more likely to discuss restrictive diets than to discuss what constitutes a healthy diet. However, since non-evidence-based restrictive diets were seen to reflect the "zeitgeist" (N1) of the time, they were disregarded by neurologists as fads that come and go. As a result, not all neurologists engaged in discussions about diet with their patients, and some were unaware of which restrictive diets were popular with pwMS.
243 244 245 246 247	3.2.4 Theme 4 The unresolved role of the neurologist in providing dietary advice  The role of the neurologist in providing dietary advice was uncertain. More than two-thirds believed they had very little influence, or even no influence, when it came to providing dietary advice to their patients. In contrast, they believed the diet 'gurus' to be very

influential. Time constraint was a common reason for not discussing diet in any detail.

Neurologists recognised the importance of autonomy for their patients, and acknowledged that diet was a way for pwMS to have a sense of control. It was generally accepted that their patients' compliance to restrictive diets would wane over time. As such, the neurologists dismissed any potential risks. Hence, discussing the pros and cons of restrictive diets was not considered a priority.

Many neurologists felt it was not their role to provide any dietary advice other than general healthy eating information, but even so they rarely referred to the *Australian Dietary Guidelines*. Some neurologists did not provide any dietary guidance. Unless a patient specifically enquired about diet, it was often not mentioned. The tension surrounding the role of the neurologist in providing dietary advice was further amplified by the limited, and often conflicting, evidence for the role of diet in MS. In contrast to disease-modifying therapies, there are very few randomised controlled trials assessing diet and MS progression, making it hard for neurologists to judge what impact diet has on MS. Although providing dietary advice was not considered part of their role, only a few neurologists directed patients to MS organisations or dietitians for dietary assessment and counselling.

### 4. Discussion

This is the first study to explore the perceptions of neurologists about diet and MS, and identify the type of dietary advice they provide to their patients. A strength of the study was that we interviewed neurologists with a range of experience, who were consulting in both the metropolitan and regional areas of WA, and in both public and private health sectors. In summary, we found that the dietary advice provided to patients was inconsistent, with the neurologists juggling the conflicting evidence around diet and MS (theme 1). A range of risks and benefits associated with the specific diets promoted for pwMS were acknowledged (theme 2). By using dismissive language and religious expressions, the neurologists distanced themselves from the 'gurus' who promote restrictive diets (theme 3). In light of the first three themes, we found that the role of the neurologist in providing dietary advice was ultimately unresolved (theme 4).

The neurologists in our study did not always follow an evidence-based approach when providing dietary advice. Given the conflicting evidence around diet and MS, there was no

clear consensus in the dietary advice provided by neurologists, despite MS organisations encouraging a diet in line with national dietary guidelines(23). This is consistent with a study of family physicians(24), where the physicians deviated from evidence-based medicine when the preferences of their patients conflicted with the evidence. In addition, when there is no clear consensus in the medical literature, patient perspectives are critical for enabling physicians to make decisions without restricting patient autonomy(24, 25).

Discussions about diet focussed on specific diets: some enabled pwMS to meet their nutrient requirements (e.g. Mediterranean diet), while others did not and were considered restrictive (e.g. Paleo diet). The Australian Dietary Guidelines were not mentioned as an example of a healthy diet, and were not considered to be a diet that could benefit pwMS. Given that less than 4% of Australians meet the recommendations of the Australian Dietary Guidelines, it is likely that following these guidelines would be a significant dietary change for pwMS(26). For pwMS, potential benefits of following the Australian Dietary Guidelines include reduced risk of co-morbidities (such as type 2 diabetes and cardiovascular disease, which increase the risk of disability progression for pwMS(27)), weight management, less constipation, and better general health(28). Such healthy eating could promote a sense of control for pwMS, while avoiding the risks associated with restrictive diets (e.g. nutrient deficiencies(29) and financial difficulties, since such diets have been described as "expensive" (5)). The neurologists did not consider nutrient deficiencies to be an issue, as they perceived compliance to such diets to be low. Nevertheless, doctors should actively monitor the nutritional status of pwMS who follow diets that are known to be restrictive and potentially limiting in specific nutrients(30).

Few neurologists in our study discussed dietary modifications as a way for their patients to potentially manage their symptoms. Given that pwMS experiment with diet as a means of symptom management(5, 31), not addressing the potential for diet to manage MS symptoms may be incompatible with patients' expectations. In addition, the potentially detrimental effects on mental health from following restrictive diets were rarely discussed. This may also be misaligned with patient expectations, since pwMS have reported social isolation from strict adherence to restrictive diets, and a fear of failure (worsening symptoms) if they stray from the diet(5).

Neurologists felt they had little influence over the dietary choices of their patients. This is contrary to previous literature on the influential nature of neurologists: pwMS value the perspectives of their neurologist on a range of information (beyond medical advice), and view them as a source of hope for therapeutic advances(13). Neurologists are the most important, reliable, and preferred source of MS information(11, 13, 32). Our findings suggest that neurologists may underestimate their influence regarding diet, since pwMS want information on all aspects of their disease management, including diet(11).

Overall, neurologists considered the provision of dietary advice (beyond "eat well") to be outside their role. This is consistent with oncologists, who also think providing dietary advice is outside their role(33). This viewpoint does not match the perceptions of their patients: insufficient dietary advice provided by neurologists may be considered by pwMS as a lack of knowledge about diet(5), and a lack of reliable resources can negatively affect patient engagement(34). The neurologists were dismissive of the so-called diet 'gurus' (where 'guru' was used in a disparaging way, as a person with knowledge who advocates for their particular theory(35) and has a financial interest). Nevertheless, they thought 'gurus' were influential, since they provided definitive dietary advice that gave hope to pwMS.

Neurologists should not underestimate their degree of influence when providing consistent, evidence-based dietary advice. Clear advice could enable neurologists to be as influential as the 'gurus'. This would maintain their authority as the experts, while giving their patients hope.

We applied a number of techniques to ensure rigour in this study(36); however, there are some limitations. There is the potential for self-selection bias in the participant sample, where those with an interest in diet may have been more willing to participate. We attempted to overcome this by encouraging participation from a range of neurologists, regardless of whether they provided dietary advice or not. Our findings may not be generalizable outside of Australia, since other countries may have specific clinical practice guidelines with respect to diet and MS.

### 5. Conclusion

PwMS prefer to receive information about MS from their neurologists than from any other source. Neurologists could meet the expectations of their patients with MS by providing

- evidence-based dietary advice. They could direct patients to resources such as the
- 349 Australian Dietary Guidelines and highlight the ways that this diet may be beneficial, while
- discussing the potential risks of restrictive diets and referring patients to dietitians. Future
- resources could be developed to help neurologists illustrate the potential benefits of the
- 352 Australian Dietary Guidelines for pwMS. Further research is needed to elucidate how
- 353 neurologists could provide dietary advice within their current time constraints, and improve
- 354 their self-perceived influence regarding giving dietary advice.

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