BARRIERS AND MOTIVATORS FOR TOBACCO SMOKING CESSATION IN PEOPLE WITH MULTIPLE SCLEROSIS

Assunta Hunter, PhD[1], Lisa B. Grech, PhD [2,3,4,5], Ron Borland, PhD [3,6,7], Roshan das Nair, PhD [8,9], Sarah L. White, PhD [10], Claudia H Marck, PhD [1]

[1] *Disability and Health Unit, Centre for Health Equity, The Melbourne School of Population and Global Health, the University of Melbourne, Melbourne, Australia*

[2] *Department of Health Sciences, Swinburne University, Melbourne, Australia*

[3]*Melbourne School of Psychological Sciences, the University of Melbourne, Melbourne, Australia Division of Psychiatry & Applied Psychology, School of Medicine, University of Nottingham, United Kingdom*

[4] *Department of Cancer Experiences Research, Peter MacCallum Cancer Centre, Melbourne, Australia*

[5] Clinical Sciences at Monash Health, Medicine, Nursing and Health Sciences, Monash University

[6] *Cancer Council Victoria, Melbourne, Australia*

[7] *The Melbourne School of Population and Global Health, the University of Melbourne, Melbourne, Australia*

[8] *Division of Psychiatry & Applied Psychology, School of Medicine, University of Nottingham, United Kingdom*

[9] *Institute of Mental Health, Nottingham, United Kingdom*

[10] *Quit Victoria, Cancer Council Victoria, Melbourne, Australia*

*Corresponding author

Claudia.marck@unimelb.edu.au

207 Bouverie Street, Carlton 3065

Victoria, Australia

ABSTRACT

Introduction: Smoking is a key modifiable risk factor for health outcomes of people with multiple sclerosis (MS). Little evidence exists on whether the information and support needs of people with MS who smoke are met. This study aimed to explore knowledge, attitudes and beliefs about smoking and quitting, and quitting support needs in Australian people with MS.

Methods: Current and recent smokers were recruited for phone interviews through social media and newsletters. Interview data were analysed in NVivo using framework analysis.

Results: We interviewed 25 people with MS (20 current and five recent smokers). Many participants had little knowledge about the risks of smoking on MS progression. Some reported perceived benefits from smoking on MS symptoms, while others perceived smoking worsening their symptoms. Similarly, quitting was believed to have health benefits, but concerns about withdrawal symptoms and the impact on MS symptoms and relapses were common. Participants reported ambivalence discussing smoking with clinicians; some wanting more information and support, while also feeling shame or guilt. Many participants were asked about their smoking status by MS clinicians, however, the provision of evidence-based information, and referrals to quitting support services was very infrequent. General practitioners were often found helpful and supportive, but participants gave more weight to quit advice from MS clinicians.

Conclusion: Our results are the first to indicate that smoking cessation needs of Australian people with MS are not met. These findings should be confirmed in a larger sample, but there is potential to investigate whether implementing routine provision of brief advice in MS care, as a coordinated effort between MS researchers, practitioners, consumer advocates and behavioural intervention services, may meet these needs. Further, developing targeted resources and training quit counsellors to provide appropriate information and support specific to people with MS may improve smoking cessation success in people with MS.

Key words: Multiple sclerosis, tobacco smoking, qualitative, cessation, modifiable risk factor,

Acknowledgements

We thank Jodi Haartsen and Andrew Giles from Multiple Sclerosis Australia for their contributions to the interpretation of the data.

Funding

This work was supported by The University of Melbourne; Quit Victoria; Multiple Sclerosis Research Australia (grant number 19-0643) and the National Health and Medical Research Council (Early Career Fellowship CHM, grant number 1120014).

Declaration of Conflicting Interests

SLW works for Cancer Council Victoria, a not-for-profit organisation delivering the Quitline in Victoria, Australia. The authors declare no other conflicting interests.

1. INTRODUCTION

Over 25,000 people in Australia live with Multiple Sclerosis (MS) (Campbell et al., 2019), a chronic neurological disorder, likely caused by a complex interaction between genetic, environmental and lifestyle factors (Olsson et al., 2016). A key determinant for MS onset is tobacco smoking, increasing the odds by approximately 50% compared to never smokers (Hedstrom, 2019). Tobacco smoking also increases risk of MS progression (Hempel et al., 2017a) and premature mortality (Manouchehrinia et al., 2014), and may impair the efficacy of MS disease modifying therapies (Hedstrom et al., 2014a; Hedstrom et al., 2014b).

Maintaining neurological reserve and brain health is a key part of MS management and smoking cessation has been identified as one of the main modifiable risk factors for maintaining brain function (Giovannoni et al., 2016). Longitudinal studies indicate that smoking cessation can slow down disability progression (Tanasescu et al., 2017) and MS progression (Ramanujam et al., 2015). Recent recommendations for maintaining brain health suggest that people with MS should receive an annual lifestyle assessment from a MS healthcare professional (Giovannoni et al., 2016). However, there are no specific strategies to promote smoking cessation for people with MS, or at high risk for MS (Marck et al., 2019b). The National Institute for Health and Care Excellence (NICE) guidelines for managing MS suggests clinicians use their smoking cessation guidelines for people with chronic diseases to support people with MS to quit (National Institute for Health and Care Excellence, 2014, 2018), but recent research suggests this rarely happens in clinical practice (Headstrong Thinking Limited, 2018).

It is unclear whether there are MS-specific barriers to smoking cessation, which may warrant strategies beyond those that are currently developed for the general population (Marck et al., 2019a). A 2006 North American study reported that people with MS perceived benefits of smoking for coping with MS symptoms, and that many had unsuccessfully attempted to quit; quoting withdrawal symptoms and barriers to accessing smoking cessation aids (Friend et al., 2006). However, this study did not explore knowledge of the impact of smoking on health and MS specifically, if and how people with MS were assisted to quit, and what may increase cessation success. An unpublished UK MS Society study (n=27), discovered that nearly all people with MS who smoked or quit had no knowledge of the MS-specific risks of smoking (Headstrong Thinking Limited, 2018). The study found that people with MS who smoked displayed many of the same barriers to smoking cessation as people who smoke within the general population, *and* MS-specific barriers, such as coping with the high stress levels due to living with MS.

Given the paucity of recent research evidence, and urgent calls to promote smoking cessation among people with MS (Amato et al., 2017; Hempel et al., 2017b; Newland et al., 2017; Tanasescu et al., 2017), more research is needed to understand the specific needs of people with MS, and whether these are met (Marck et al., 2019a). Our study aimed to provide a detailed insight into the beliefs, behaviours and attitudes of people with MS regarding tobacco smoking, as well as their needs for smoking cessation assistance, and barriers and facilitators to smoking cessation within an Australian context.

2. METHODS

2.1. RESEARCH DESIGN

A stakeholder group, including smoking cessation experts, MS advocates and MS clinicians, informed the design of the study. The semi-structured interview guide (Appendix 1) was designed by members of the research team (CHM, LBG, RB, RdN, SW) and stakeholder group based on literature review (Marck et al., 2019a), expertise, previously developed qualitative interviews (unpublished) and clinical experience. The interview guide was refined iteratively with members of the research team and stakeholders. We consulted and used the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007). Ethics Approval was obtained through the University of Melbourne Human Research Ethics Committee (Ethics ID 1954916.1).

2.2. RESEARCH TEAM AND REFLEXIVITY

Interviews were conducted by one of the researchers (AH) with relevant experience in qualitative research. There was no established relationship between the interviewer and any of the participants, and the interviewer had little prior knowledge about, or personal interest in the topic prior to starting the interviews. Some of the authors were previous smokers, none were current smokers; and one of the authors has a diagnosis of MS.

2.3. PARTICIPANT RECRUITMENT

Participants were eligible if they had a diagnosis of MS, lived in Australia, and were current cigarette smokers (smoking at least once weekly) or had given up smoking in the last two years. Participants were recruited between September 2019 and January 2020 through online social media (Facebook, Twitter), newsletters and websites of MS organisations (Australian MS Longitudinal Study, MS Research Australia, MS Australia, MStrials.org.au). Participants contacted the researcher if they had seen the recruitment advertisement and provided consent before interviews commenced. Participant recruitment ceased when data saturation had been reached (Francis et al., 2010; Saunders et al., 2018). This judgement was made by the interviewer (AH) who was concurrently analysing the data while the interviews were proceeding, in consultation with other authors (CM, LG).

2.4. DATA COLLECTION

Semi-structured interviews lasted 30-60 minutes. We collected demographic characteristics and ascertained participants' level of disability using the Patient Determined Disease Steps (PDDS)(Learmonth et al., 2013). On this scale, 0-2 is low level disability indicating no sensory symptoms and low impacts on everyday life. Moderate (3-5) indicates early impairment of gait including use of canes and symptoms that limit daily activities. Severe (6-8) signifies severe symptoms requiring two canes or a wheelchair and extends to being bedridden (8). Probing questions and some conversational interchange was undertaken during the interview. Interviews were audio recorded and transcribed verbatim by a professional transcription agency, and were not returned to participants for further comment.

2.5. DATA ANALYSIS

The interviewer and another author used NVivo (12 plus) to code data for framework analysis (Houghton et al., 2017), which combines the use of *a priori* assumptions and the desire to answer specific questions with the capacity to include emergent themes from the data (Kiernan and Hill, 2018; Srivastava and Thomson, 2009). Patterns in the data were identified, analysed and categorised into themes and using the framework model into a succession of sub-themes (Ritchie et al., 2003). Further refinement of these themes, and the development of recommendations, occurred in dialogue with the other researchers and the stakeholder group. Quotes provided below include information about whether the participant was at the time of interview a smoker (S), non-smoker (NS), and their level of disability (mild, moderate, severe). We used a reporting scale which gives some indication of the proportion of the sample who fell into specific categories. A few = less than 25%, some = 25-39%, half = 40-60%, many = 61-75% and most =>75% (Maxwell, 2010; Neale et al., 2014). Given this is a qualitative research study, we caution against any attempt to infer that the noted proportions are indicative of prevalence outside of this sample.

3. RESULTS

3.1. PARTICIPANT DEMOGRAPHICS

We were contacted by 33 potential participants, resulting in 25 participant interviews (see Table 1). Of the eight people not included, three chose not to participate, two had stopped smoking more than two years ago, two made contact following recruitment completion, and one was not a weekly cigarette smoker. Ten saw their neurologists privately, 13 in public hospital MS clinics and two in general neurology clinics.

Table 1. Demographic and clinical characteristics of participants

Demographic and clinical variables		**Number**
Gender	Men	9
	Women	16
Age in years	30-39	11
	40-49	7
	50-59	6
	60-69	0
	70-79	1
Employment	Not employed	10
	Employed part or full time	15
State of residence	Victoria	7
	New South Whales	7
	South Australia	3
	Queensland	2
	Western Australia	5
	Tasmania	1
Remoteness	Urban	16
	Regional	7
	Remote	2
Age at diagnosis	20-29	6
	30-39	9
	40-49	8
	50-59	2
Type of MS	Secondary Progressive	2
	Primary Progressive	3
	Relapsing Remitting	20

Level of disability	None/mild	4
	Moderate	16
	Severe	5
Smoking Habits	Current smoker	20
	Quit in last 2 years	5
Duration of smoking	7-50 years (median 19 years)	

3.2. SMOKING HABITS

Of the current smokers, half smoked (or had smoked) between 20-40 cigarettes each day. Some smoked between 10 and 20 cigarettes a day, and some reported smoking less than 10 cigarettes per day. All but two participants smoked daily; one smoked marijuana and tobacco two or three times a week and had smoked tobacco without marijuana as well; their responses regarding marijuana use were not analysed. Participants would sometimes describe variable smoking levels depending on work, stress levels, severity of symptoms such as pain, or if they were "having a bad day". All participants reported attempting to quit at some point, many had tried to quit multiple times. Most of the 20 current smokers wanted to quit; only one participant said they currently did not plan to stop smoking, and two participants were unclear or ambivalent when asked whether they planned to stop smoking in the future.

3.3. MOTIVATION TO CONTINUE SMOKING

Participants' reasons for smoking included stress relief, social pressure, as a distraction and a way of having some time out, something to do when they were isolated, unable to work or when their mood was low. More specific to MS was the belief that smoking maintained some sense of normality and identity in the face of the many losses associated with MS (Text box 1). When initially asked, most indicated they couldn't see any benefits of smoking. However, some subsequently mentioned perceived benefits on symptoms like pain or spasticity, which they believed would increase when cutting down smoking or that smoking (or the nicotine) helped with mobility. Smoking was linked with feelings of anxiety related to MS and health more generally. Some reported that knowing the impact of smoking on MS was stress-inducing, further increasing feelings of anxiety and increasing subsequent smoking.

Text box 1. Motivation to continue smoking

“MS, it's taken away my career, my ability to have children, my driver’s license… It's just taken everything away from me, and that’s the one thing I feel I’ve got left is just my smoking, and I’m not going to let it take that away from me.” (Interview 11 S PDDS severe)

“I don’t, well there's really zero benefits, like I can fool myself and say it helps with my brain fog, with my cognitive issues. Because the nicotine does stimulate your brain a little bit. Strangely enough when I get up in the morning with my spasticity I don’t walk very well, and I sit down and have a cigarette and I get up and walk alright. So I don't know what that is, if that’s just something being triggered in my brain.” (Interview 13 S PDSS moderate)

“And I strongly, I don't know whether it was a placebo or whether it was real, but I think it helped my pain… at the time I didn’t know it was MS pain, but it was kind of like instead of turning to alcohol or – I didn’t really like taking strong medication, so I would, I sort of used that – and yeah I don't know if it was mental or if it was real.” (Interview 9 NS PDDS moderate)

“And I’m finding since my diagnosis I’m smoking more now than what I probably smoked in the last 10 years, and the stress of knowing that smoking impacts my MS increases my anxiety which seems to make me smoke more.” (Interview 17 S PDDS moderate).

“I would sit and think every single puff that I’m having is just damaging my MS more, it's – and I was sitting there and I was going to bed crying of a night time, I’m just killing myself, and I have little children, and I’d just cry myself to sleep like I’ve got to stop, I’ve got to stop, I’m just killing myself”. (Interview 10 S PDDS severe)

3.4. Barriers and facilitators to smoking cessation

Participants described their struggles to stop smoking, which most understood to be an addiction, and also described the immediacy of their need for nicotine. The influence of family, and close friends on smoking was an important component of continued smoking. Motivators to quit included families (pregnancy, children and partners), the cost of cigarettes, the effect on MS symptoms, chronic lung disease, and other health issues associated with smoking, including its effects on sexual function. Quitting was associated with stress and anxiety. Participants feared the negative effects of quitting on mood and relationships. Specific mentions were made about the effects that quitting and associated stress may have on MS symptoms and a potential relapse (Text box 2).

Text box 2. Barriers and facilitators to smoking cessation

“It really affected my walking, and I felt like every time I had a cigarette it was, it flared up my symptoms” (Interview 27 NS PDDS moderate)

“…as soon as I was diagnosed I was like that’s it, I have to quit, otherwise I’ll end up in a wheelchair and it’ll be my own fault” (Interview 9 NS PDDS moderate)

“I’ve weighed up the pros and cons of smoking and not smoking, and for my mental health I’ve chosen to continue to smoke, rather than give up and – because I just think I would become too sad if I gave up, too depressed if I gave up. I don’t think I could do it mentally, I honestly don’t think I could.” (Interview 11 S PDSS severe)

“I’ve dramatically cut back on my smoking, but yet the last 3 nights my pain in my legs has been more intense than normal.” (Interview 10 S PDDS severe)

“I quite often go 3 or 4 days without a cigarette, I do get a bit moody and a bit cloudy in the brain and perhaps even a little bit depressed you know… they're probably the part that drive me back towards the cigarettes…” (Interview 13 S PDDS moderate)

“I know that it’ll also have an effect on my parenting, I know, I am absolutely terrified that that stress bubble of craving a cigarette ignites a relapse and I’m just, I have no idea what I would do, I have no plan, I have no support, like where would my child go, how would I take care of him. It actually gives me anxiety thinking about it.” (Interview 4 S PDDS mild)

3.5. THE KNOWLEDGE GAP

Participants had varying levels of knowledge about how smoking affected the course of MS (Text box 3). Although all knew they should quit for their general health ("*everyone knows it's bad for you*"), most participants knew very little about how, how much, and why smoking might affect their MS. Many participants reported that they had been told little more than "*smoking and MS don't mix*" or "*you just have to stop*" by their neurologists. Some participants understood that smoking may impact on their MS progression, but were unclear whether it was the tobacco, the nicotine or other substances that were harmful. Some participants said that more knowledge would increase their motivation to quit.

Some participants had found information about the MS-specific impacts of smoking through MS associations, MS support groups or via social media, but were not sure of its reliability. Most of the participants indicated they did not have enough information about the MS-specific impact of smoking and many said they would like more information including written resources, and in-depth supportive conversations with their neurologist or MS nurse. Some wanted information about whether smoking cessation medications were contraindicated, or interact with, their MS medications. Indeed, several participants asked the interviewer for specific information about the impacts of smoking on MS.

Text box 3. The knowledge gap

"The effects on my MS I would probably know less about than I do the effect on say my lungs or my respiratory system, I think because forever we're told cigarettes, you know smoking causes cancer and you die." (Interview 15 S PDDS mild)

"I have not been told anything in 7 years, 8 years about smoking and MS." (Interview 2 NS PDDS moderate)

"You know I've been told by the doctors and all that sort of stuff to give up smoking for general health and all that, but never really specifically for MS". (Interview 11 S PDDS severe)

"I'm sure at the time of my diagnosis if they had've told me the very best thing I could do for my MS would be to stop smoking and there was stuff in place to give me guidance with that or counselling with that, I'm sure that would've helped, I'm sure 20 years ago I would've given up." (Interview 13 S PDDS moderate)

" I know that there's a medication that you can take now it's called Champix. I don't know if that's contraindicated with people with MS or not." (Interview 4 S PDDS Mild)

3.6. SUPPORT FOR QUITTING

Most participants knew about a range of quitting supports and most had used these in the past. Therapeutic support considered useful from previous attempts at quitting included nicotine replacement therapies (NRTs), smoking cessation drugs (varenicline and bupropion), hypnosis, cold turkey, 12 step programs, and phone apps (that provided motivation and sent encouraging messages). Many reported side-effects from smoking cessation drugs. Many participants knew about Quitline, Australia's population-level multi-session behavioural intervention service, and some had used it and found it useful at that time. However, participants indicated there was a lack of MS-specific resources or knowledge, and some were under the impression that support came mostly in the form of text messages rather than conversations (the latter was preferred). Some participants expressed a preference for quitting messages to be delivered by people with MS knowledge (Text box 4).

Plans for future quitting attempts included discussions with a GP, counselling support, NRTs, and unassisted ("cold turkey") attempts. Counselling was found helpful with both the quitting process and with support for the uncertainties associated with MS as a disease. Several participants wanted more intensive support to help them quit.

Text box 4. The knowledge of support for quitting

> *"I need to sort of like see the anatomy and physiology, or the clinical aspects of the link of smoking to MS. I can't just look at, go to the Quitline and look at this generic version of well this is how smoking affects you…"* (Interview 30 S PDDS moderate)
>
> *"To break the habit I think they'd need to discuss it with me frequently. I need somebody to hold me accountable because clearly I'm not strong enough to be accountable myself. And I also need to know that if I start feeling altered sensations or something else, that it is a case of getting the nicotine out of my body and not a case of this means a relapse. So I need that added security, and it's probably the one thing that's holding me back, is not feeling like I've got it."* (Interview 4 S PDDS mild)

3.7. COMMUNICATIONS WITH CLINICIANS ABOUT SMOKING

Participants were hesitant, ambivalent and sometimes in denial about discussing smoking with clinicians, expressing varying degrees of comfort about speaking to neurologists, MS nurses and GPs (Text box 5). Some participants said they would discuss smoking with a particular clinician, but never brought it up themselves; some because they knew they would get told to quit or they preferred not to know the facts. While some indicated they wanted to discuss it with their MS clinician specifically, others thought it was not a priority discussion topic for time-poor neurologists. Some participants said they were asked about their smoking by their MS clinician, but this was not followed with information or advice, nor follow-up after a quitting attempt. Others reported that the relationship with their neurologist was not conducive to having conversations about smoking.

Participants consulted their GPs more often than their MS clinicians, and many indicated they would comfortably have smoking cessation discussions with them. Some participants reported their GPs had guided them through successes and failures in quitting and continued to support them and refer them to counsellors, quit programs, cognitive behavioural therapy (CBT) and other supports in their attempts to quit.

"….they don't ask so I don't tell" (Interview 23 S PDDS moderate)

"No, I know that that information is out there, I know that it's negative and I've chosen to stay ignorant, deliberately chosen to stay ignorant. I know that that's not the best option, but for coping purposes I've just made the decision not to learn" (Interview 4 S PDDS mild)

"…there's only so many times we can be told exactly the same thing, we tend to gloss over it I suppose and become a bit blasé about it, I'll do it when I'm ready. And so I guess that's probably why I wouldn't raise it with (the neurologist) so much. And there's also a bit of fear to be told that you're really doing yourself some damage and making this worse." (Interview 15 NS PDDS mild*)*

"Probably not but I may have been told more if I was open and transparent about how much I actually smoked, that may have been higher on my neuro's radar, if she knew that I was on them again every day." (Interview 15 S PDDS mild)

"I think it holds a lot of weight when it comes from the neurologist, because they are experts in their field, obviously MS nurses are experts in their field as well, but I think both yeah, both. It needs to be reinforced from every angle..." (Interview 14 NS PDDS moderate).

" I think one of them at one point said well that needs to stop, and just kept and moved on. But never a big conversation about it, no… I don't really know if it's up to the neurologist, because their time is precious... (Interview 9 S PDDS moderate)

"Although, no, no my neurologist has never asked me if I smoke. My MS nurse I said to them you know I smoke, I need to stop smoking, how am I going to stop smoking. And their response to me was: do as I say not as I do, so they must be a smoker, and they said just you need to just put it in your long term list of things to do, they said, do not try and stop smoking now." (Interview 17 S PDDS moderate)

"Not very comfortable at all. My neurologist doesn't really see you as a person, you're just a number for him… I don't think he actually cares what's going to go on" (Interview 1 NS PDDS mild).

"He (the GP) sure did yeah, yeah, there was no judgement in it, it was good on you, let's do this. And I really felt like I had someone on my side" (Interview 15 NS PDDS mild)

Text box 5. Communications with clinicians about smoking

3.8. When and if to discuss smoking cessation with MS clinicians

Some participants said more regular discussions about smoking would be welcome if they were supportive and informative and if they led to active support for smoking cessation including follow-up, referrals and prescribing. By contrast when asked how they would feel if clinicians never asked about smoking about half the participants said they would not mind, whereas the other half felt it was a sign of indifference or even disregard. One person said she was discouraged from quitting by her MS nurse. Some participants thought at the time of diagnosis, when they were most motivated to make changes, was the best time to discuss smoking cessation, whereas others thought this may be overwhelming (Text box 6).

Text box 6. When and if to discuss smoking cessation with MS clinicians

“that would’ve been a good wake up call for me at diagnosis, and that’s when I was sort of changing my life, or my life had changed, that would’ve been the ideal time to have the support then to stop smoking. Better information and better support and you know a bit of coaching would’ve been good at that time.” (Interview 13 S PDDS moderate)

“After they’ve got over the shock of diagnosis, certainly not at diagnosis because it's such a shock when you get told that you’ve been diagnosed with the disease, I think the last thing you'd want, if you're a smoker, hard core smoker, the last thing you'd want to hear is now you need to give up smoking” (Interview 11 S PDDS severe)

“I think it needs to be done when you're diagnosed, but I certainly think it needs to be followed up, because you’ve got so much going on when you're diagnosed…, yeah, every 6 months and keep going for a couple of years I’d say” (Interview 18 S PDDS moderate)

“if they were doing it in a bullying way, I wouldn’t like it at all. But if they were being supportive and gentle about it, I would think thank you you’ve got my best interests at heart, I appreciate that” (Interview 11 S PDDS severe)

"I would think it would be very remiss, and I would question, I would question their professionalism, because I think it's a very important question to ask, as much as I dread the question." (Interview 11 S PDDS severe)

“I would just assume that they wouldn’t care. Or that it wasn’t a problem, or that it wasn’t bad for me, or that you know it's not part of the bigger picture, it would basically dismiss any obligation I guess of having to be accountable for it.” (Interview 4 S PDSS mild)

4. DISCUSSION

Many of the ways that participants described their experiences with smoking, their difficulty in their attempts at quitting were very similar to the experiences of other groups of smokers (Buczkowski et al., 2014; Campbell et al., 2018; Twyman et al., 2014). Our results, with a particular focus on MS-related barriers to smoking cessation provides novel evidence that developing strategies to address MS-specific barriers may improve quit attempts and smoking cessation outcomes.

Many participants felt their information and support needs were not met when it came to smoking cessation, in particular the lack of information about the impact of smoking or quitting on health, assistance, referral, or follow-up was noted. Worsening of symptoms of anxiety and depression, and the flow-on effects on relationships and potential MS relapses were a concern for many participants relating to quitting smoking. People with MS already experience higher levels of anxiety and depression and other psychiatric disorders compared to the broader population (Marrie et al., 2015; Wood et al., 2013). People with mental health difficulties have been found to experience similar barriers (Kerr et al., 2013), and support with mood symptoms might facilitate quitting (Weinberger et al., 2017). Other barriers included difficulties in accessing accurate information or advice about the effects of smoking, as well as quitting and nicotine withdrawal on MS symptoms and relapses, and concerns about the interactions between quitting medications and MS medications. Perceived ineffectiveness and/or side effects of NRTs; and conflation of the harms of tobacco and nicotine products has been previously reported, for example in people with HIV (Pacek et al., 2021). While there is no evidence to suggest there are interactions between cessation medication and common MS medications, there is evidence that smoking interferes with some MS medication efficacy (Petersen et al., 2018a; Petersen et al., 2018b). That none of the participants mentioned this possibility, and the general lack of awareness of the harms of smoking for MS, indicates an important knowledge gap, in line with a previous report (Headstrong Thinking Limited, 2018). Other research with people with chronic illness such as rheumatoid arthritis (Aimer et al., 2015) and diabetes (Georges et al., 2019) report similar knowledge gaps and needs for specific disease-related cessation support.

Most participants reported they had been asked about smoking by MS clinicians, but perhaps only once, and were simply told to quit, without further information about the impact of smoking or quitting on health, assistance, referral, or follow-up. Indeed, assessing smoking status without providing advice or support might suppress quitting (U.S. Department of Health and Human Services, 2020). Inadequate smoking cessation care has been reported previously in studies with other priority populations, e.g. pregnant women (Campbell et al., 2018) including Australian Indigenous women (Rahman et al., 2021), and people with chronic illness (Georges et al., 2019; Kerr et al., 2013). Salient 'information about health consequences' is an essential ingredient of successful interventions for other groups (Campbell et al., 2018). Many of our participants wanted this information, however, others indicated this knowledge increased their feelings of guilt and anxiety. Indeed, this ambivalence between wanting more information and support to quit, but simultaneously avoiding the conversation has been previously reported in people with other chronic illness (Gritz et al., 2006; Pacek et al., 2021). Strengths-based approaches should be focussed on instead (Gritz et al., 2006; Rahman et al., 2021), including the individual motivations of participants to quit, the benefits of quitting, and building on support from family and friends as well as others in the MS community who have successfully quit.

Participants noted that smoking cessation was not a priority in neurology consultations for them or for neurologists. While a trusted GP may be better placed in terms of access and time, extra weight would be given to smoking cessation advice coming from neurologists or other MS clinicians who may be able to offer MS-specific information. Some participants highlighted the need for continued encouragement and support from "all angles". Indeed, there does not seem to be a "one size fits all" approach. Our findings suggest that a multi-pronged, long-term and person-centred approach, including respectful and informative conversations and brief interventions with clinicians would be a helpful impetus to continued quit attempts (Aveyard et al., 2012; Stead et al., 2013). Some participants in this study indicated the time of diagnosis is a "teachable moment" (McBride et al., 2003), where people are highly motivated to change health behaviours, while others thought it would be too overwhelming to try to quit at such a stressful time. Nevertheless, most evidence suggests that quitting as soon as possible after a diagnosis of chronic illness, including MS, diabetes and cardiovascular disease, is likely to yield greater benefits for the natural history of the illness (Royal College of Physicians, 2018). Participants were generally hesitant to report taking up smoking again after a quit attempt, highlighting the importance of ongoing supportive and non-judgemental conversations clinicians and people who report they have quit (but might have relapsed).

4.1. IMPLICATIONS FOR CLINICAL PRACTICE

Our results suggest that there is a lack of focus on best-practice smoking cessation promotion in MS care, which urgently needs more action. More specifically, clinicians should ask people with MS about smoking, tell them about the impacts of smoking on people with MS, encourage them strongly to quit and the best way to try quitting, and refer them to evidence-based cessation services. If appropriate, they could also provide or facilitate access to smoking cessation medications and refer back to the GP for ongoing management. MS clinicians are unlikely to have the skills, knowledge, or time to provide multi-session behavioural intervention that supports the actual process of quitting. Currently, it is unclear the extent to which smoking cessation services are aware of and able to help manage the additional MS-specific barriers to quitting successfully; a gap-analysis is needed. However, this lack of knowledge should not prevent action.

Concurrent with implementing routine provision of brief advice in MS care, a coordinated effort between MS researchers, practitioners, consumer advocates and behavioural intervention services is required to ensure counsellors are trained to provide appropriate information and support to encourage smoking cessation in people with MS. Based on our findings, and experience and expertise of our research team and stakeholder group, relevant literature including the recommendations of internationally recognised clinical guidelines, produced by the US Preventive Services Task Force (US Preventive Services Task Force, 2021) and the UK National Institute of Health & Clinical Care Excellence (National Institute for Health and Care Excellence, 2018), the development of the resources specified in Table 2 may be considered to improve smoking cessation support for people with MS in the medium to long term. The delivery of salient brief advice is recognised as international best practice smoking cessation care (National Institute for Health and Care Excellence, 2018; US Preventive Services Task Force, 2021). Materials to support health education and literacy for consumers and health professionals and to ensure appropriate psychoeducation is provided during behavioural interventions were identified as current gaps by the stakeholders. Pathways between MS and cessation services were identified as an opportunity to support continuity of care.

Table 2. Recommendations and proposed resources to support clinician practice

Recommendations for resource development	Target audience
1. Guidance and training to deliver best-practice salient brief advice for smoking cessation; ideally for use at initial consultation and once-yearly there-after.	MS clinicians
2. Evidence-based resources that provide information on: • the effect of smoking and passive smoking on MS disease progression • the benefits of quitting for MS and general health • potential side-effects of nicotine withdrawal and cessation medication (so these are not misinterpreted as worsening of MS symptoms or a relapse) • medication interactions with smoking cessation medications • availability and effectiveness of multi-session behavioural intervention (to maximise engagement by people with MS) • success stories from a diverse range of people with MS who quit smoking • links to smoking cessation tools, resources, and calculators	People with MS Carers and family MS clinicians

3.	Cross-referral pathways between the smoking cessation service and other MS-specific services should be developed to ensure appropriate and comprehensive support is provided to people with MS. • Symptoms of pain, anxiety and depression are prevalent for people with MS and could be compounded by smoking cessation attempts. Symptom management may need to be increased when quitting. • Counselling may assist those who are fearful that quitting-related stress may induce a relapse. • Extra support for people with cognitive impairment, such as problems with impulse control or those who may have difficulties in retaining information, which may require provision of detailed written information, one-on-one behaviour change strategy development, longer or higher intensity follow-up services.	MS clinicians and services Behavioural intervention counsellors
4.	Development of MS specific information and educational resources that address MS-specific information and support needs	Behavioural intervention counsellors

4.2. STRENGTHS AND LIMITATIONS

There is debate about the extent to which social desirability bias may influence results in studies about smoking habits (Luepker et al., 1989; Moskowitz, 2004). We aimed to mitigate this through use of telephone interviews in an effort to reduce shame and stigma felt by smokers, which may have enabled more fulsome and honest responses (Bell et al., 2010). There were advantages in discussing the topic of smoking on the phone in that it allowed interviewees relative anonymity and it enabled interviews with people with MS living outside of urban centres, with limited mobility and thus a more widely spread sample. Consistent with the aims of qualitative research to gain in-depth information about a topic and coupled with our recruitment methods (social media and email newsletters), our study sample should not be considered representative of all people with MS in Australia. For example, while our participants ranged in age, level of disability and disease duration; most were aged below 50 years, whereas a recent study using a large dataset of people with MS in Australia reported that most participants were aged over 50 years (Marck et al., 2020). The transferability of these results must therefore be treated with caution, also given the small number of participants. Our findings should be confirmed by larger scale quantitative research, as well as studies in other countries where the healthcare system, tobacco control policies, and cultural values may differ. Larger studies on this topic are warranted and should investigate the role of demographic factors, level of disability, nicotine dependence, and other potential confounders on perceptions and attitudes regarding smoking and cessation supports, as well as the role of e-cigarettes. Finally, population level tobacco control measures and social determinants of health are likely influencing smoking and cessation attitudes and behaviours, which should be taken into account.

5. CONCLUSIONS

Our findings, from people with MS in Australia, indicate that information and support needs for smoking cessation are not being met. Generally, participants had a poor understanding of how smoking or quitting might affect their MS symptoms, MS medications, the course of their disease and its long-term outcomes. Despite a reluctance to raise the subject of smoking with their MS healthcare providers, the majority of participants would be accepting of repeated enquiry, evidence-based information, and offers of support for cessation assistance; provided it was delivered in a collaborative, rather than authoritative, manner. Based on our findings, we provide preliminary recommendations to improve integration of, and access to, information and smoking cessations services for people with MS in the medium to long term, as well as advice for MS clinicians on what actions can be undertaken in the short term. Our findings require confirmation in a larger sample, but indicate that MS specific smoking cessation supports that address identified barriers are urgently needed to improve quitting success among people with MS.

6. REFERENCES

Aimer, P., Stamp, L., Stebbings, S., Valentino, N., Cameron, V., Treharne, G.J., 2015. Identifying barriers to smoking cessation in rheumatoid arthritis. Arthritis Care Res (Hoboken) 67(5), 607-615.

Amato, M.P., Derfuss, T., Hemmer, B., Liblau, R., Montalban, X., Soelberg Sorensen, P., Miller, D.H., Group, E.F.W., 2017. Environmental modifiable risk factors for multiple sclerosis: Report from the 2016 ECTRIMS focused workshop. Mult Scler, 1352458516686847.

Aveyard, P., Begh, R., Parsons, A., West, R., 2012. Brief opportunistic smoking cessation interventions: a systematic review and meta-analysis to compare advice to quit and offer of assistance. Addiction 107(6), 1066-1073.

Bell, K., Salmon, A., Bowers, M., Bell, J., McCullough, L., 2010. Smoking, stigma and tobacco 'denormalization': Further reflections on the use of stigma as a public health tool. A commentary on Social Science & Medicine's Stigma, Prejudice, Discrimination and Health Special Issue (67: 3). Social science & medicine 70(6), 795-799.

Buczkowski, K., Marcinowicz, L., Czachowski, S., Piszczek, E., 2014. Motivations toward smoking cessation, reasons for relapse, and modes of quitting: results from a qualitative study among former and current smokers. Patient preference and adherence 8, 1353.

Campbell, J.A., Simpson, S., Jr., Ahmad, H., Taylor, B.V., van der Mei, I., Palmer, A.J., 2019. Change in multiple sclerosis prevalence over time in Australia 2010-2017 utilising disease-modifying therapy prescription data. Mult Scler, 1352458519861270.

Campbell, K.A., Fergie, L., Coleman-Haynes, T., Cooper, S., Lorencatto, F., Ussher, M., Dyas, J., Coleman, T., 2018. Improving Behavioral Support for Smoking Cessation in Pregnancy: What Are the Barriers to Stopping and Which Behavior Change Techniques Can Influence Them? Application of Theoretical Domains Framework. International Journal of Environmental Research and Public Health 15(2).

Francis, J.J., Johnston, M., Robertson, C., Glidewell, L., Entwistle, V., Eccles, M.P., Grimshaw, J.M., 2010. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. Psychology and Health 25(10), 1229-1245.

Friend, K.B., Mernoff, S.T., Block, P., Reeve, G., 2006. Smoking rates and smoking cessation among individuals with multiple sclerosis. Disabil Rehabil 28(18), 1135-1141.

Gascoyne, C.R., Simpson, S., Jr., Chen, J., van der Mei, I., Marck, C.H., 2019. Modifiable factors associated with depression and anxiety in multiple sclerosis. Acta Neurol Scand 140(3), 204-211.

Georges, A., Galbiati, L., Clair, C., 2019. Smoking in men and women with type 2 diabetes: A qualitative gender-sensitive exploration of barriers to smoking cessation among people with type 2 diabetes. PLoS One 14(8), e0221783.

Giovannoni, G., Butzkueven, H., Dhib-Jalbut, S., Hobart, J., Kobelt, G., Pepper, G., Sormani, M.P., Thalheim, C., Traboulsee, A., Vollmer, T., 2016. Brain health: time matters in multiple sclerosis. Multiple sclerosis and related disorders 9, S5-S48.

Gritz, E.R., Fingeret, M.C., Vidrine, D.J., Lazev, A.B., Mehta, N.V., Reece, G.P., 2006. Successes and failures of the teachable moment. Cancer 106(1), 17-27.

Headstrong Thinking Limited, 2018. Exploring the potential to use communication to change behaviour among people with MS who are smokers.

Hedstrom, A.K., 2019. Smoking and its interaction with genetics in MS etiology. Mult Scler 25(2), 180-186.

Hedstrom, A.K., Alfredsson, L., Lundkvist Ryner, M., Fogdell-Hahn, A., Hillert, J., Olsson, T., 2014a. Smokers run increased risk of developing anti-natalizumab antibodies. Mult Scler 20(8), 1081-1085.

Hedstrom, A.K., Ryner, M., Fink, K., Fogdell-Hahn, A., Alfredsson, L., Olsson, T., Hillert, J., 2014b. Smoking and risk of treatment-induced neutralizing antibodies to interferon beta-1a. Mult Scler 20(4), 445-450.

Hempel, S., Graham, G.D., Fu, N., Estrada, E., Chen, A.Y., Miake-Lye, I., Miles, J.N., Shanman, R., Shekelle, P.G., Beroes, J.M., Wallin, M.T., 2017a. A systematic review of modifiable risk factors in the progression of multiple sclerosis. Mult Scler 23(4), 525-533.

Hempel, S., Graham, G.D., Fu, N., Estrada, E., Chen, A.Y., Miake-Lye, I., Miles, J.N., Shanman, R., Shekelle, P.G., Beroes, J.M., Wallin, M.T., 2017b. A systematic review of the effects of modifiable risk factor interventions on the progression of multiple sclerosis. Mult Scler 23(4), 513-524.

Houghton, C., Murphy, K., Meehan, B., Thomas, J., Brooker, D., Casey, D., 2017. From screening to synthesis: using nvivo to enhance transparency in qualitative evidence synthesis. Journal of clinical nursing 26(5-6), 873-881.

Kerr, S., Woods, C., Knussen, C., Watson, H., Hunter, R., 2013. Breaking the habit: a qualitative exploration of barriers and facilitators to smoking cessation in people with enduring mental health problems. BMC Public Health 13, 221.

Kiernan, M.D., Hill, M., 2018. Framework analysis: a whole paradigm approach. Qualitative Research Journal.

Learmonth, Y.C., Motl, R.W., Sandroff, B.M., Pula, J.H., Cadavid, D., 2013. Validation of patient determined disease steps (PDDS) scale scores in persons with multiple sclerosis. BMC neurology 13(1), 37.

Luepker, R.V., Pallonen, U.E., Murray, D.M., Pirie, P.L., 1989. Validity of telephone surveys in assessing cigarette smoking in young adults. American Journal of Public Health 79(2), 202-204.

Manouchehrinia, A., Weston, M., Tench, C.R., Britton, J., Constantinescu, C.S., 2014. Tobacco smoking and excess mortality in multiple sclerosis: a cohort study. J Neurol Neurosurg Psychiatry 85(10), 1091-1095.

Marck, C.H., das Nair, R., Grech, L.B., Borland, R., Constantinescu, C.S., 2019a. Modifiable risk factors for poor health outcomes in multiple sclerosis: The urgent need for research to maximise smoking cessation success. Multiple Sclerosis Journal, 1352458519858730.

Marck, C.H., das Nair, R., Grech, L.B., Borland, R., Constantinescu, C.S., 2019b. Modifiable risk factors for poor health outcomes in multiple sclerosis: The urgent need for research to maximise smoking cessation success. Mult Scler, 1352458519858730.

Marck, C.H., Learmonth, Y.C., Chen, J., van der Mei, I., 2020. Physical activity, sitting time and exercise types, and associations with symptoms in Australian people with multiple sclerosis. Disabil Rehabil, 1-9.

Marrie, R.A., Reingold, S., Cohen, J., Stuve, O., Trojano, M., Sorensen, P.S., Cutter, G., Reider, N., 2015. The incidence and prevalence of psychiatric disorders in multiple sclerosis: a systematic review. Multiple Sclerosis Journal 21(3), 305-317.

Maxwell, J.A., 2010. Using numbers in qualitative research. Qualitative inquiry 16(6), 475-482.

McBride, C.M., Emmons, K.M., Lipkus, I.M., 2003. Understanding the potential of teachable moments: the case of smoking cessation. Health Education Research 18(2), 156-170.

Moskowitz, J.M., 2004. Assessment of cigarette smoking and smoking susceptibility among youth: Telephone computer-assisted self-interviews versus computer-assisted telephone interviews. Public Opinion Quarterly 68(4), 565-587.

National Institute for Health and Care Excellence, 2014. Multiple sclerosis in adults: management. Clinical guideline. https://www.nice.org.uk/guidance/cg186.

National Institute for Health and Care Excellence, 2018. Stop smoking interventions and services. NICE guideline. https://www.nice.org.uk/guidance/ng92.

Neale, J., Miller, P., West, R., 2014. Reporting quantitative information in qualitative research: Guidance for authors and reviewers.

Newland, P., Flick, L., Salter, A., Dixon, D., Jensen, M.P., 2017. The link between smoking status and co-morbid conditions in individuals with multiple sclerosis (MS). Disabil Health J.

O'Gorman, C.M., Broadley, S.A., 2016. Smoking increases the risk of progression in multiple sclerosis: A cohort study in Queensland, Australia. J Neurol Sci 370, 219-223.

Olsson, T., Barcellos, L.F., Alfredsson, L., 2016. Interactions between genetic, lifestyle and environmental risk factors for multiple sclerosis. Nature Reviews Neurology 13, 25.

Pacek, L.R., Holloway, A.D., Cropsey, K.L., Meade, C.S., Sweitzer, M.M., Davis, J.M., Joseph McClernon, F., 2021. Experiences With Smoking Cessation Attempts and Prior Use of Cessation Aids in Smokers With HIV: Findings From a Focus Group Study Conducted in Durham, North Carolina. AIDS Educ Prev 33(2), 158-168.

Petersen, E.R., Oturai, A.B., Koch-Henriksen, N., Magyari, M., Sorensen, P.S., Sellebjerg, F., Sondergaard, H.B., 2018a. Smoking affects the interferon beta treatment response in multiple sclerosis. Neurology 90(7), e593-e600.

Petersen, E.R., Sondergaard, H.B., Laursen, J.H., Olsson, A.G., Bornsen, L., Soelberg Sorensen, P., Sellebjerg, F., Bang Oturai, A., 2018b. Smoking is associated with increased disease activity during natalizumab treatment in multiple sclerosis. Mult Scler, 1352458518791753.

Ponsonby, A.L., Lucas, R.M., Dear, K., van der Mei, I., Taylor, B., Chapman, C., Coulthard, A., Dwyer, T., Kilpatrick, T.J., McMichael, A.J., Pender, M.P., Valery, P.C., Williams, D., 2013. The physical anthropometry, lifestyle habits and blood pressure of people presenting with a first clinical demyelinating event compared to controls: the Ausimmune study. Mult Scler 19(13), 1717-1725.

Rahman, T., Eftekhari, P., Bovill, M., Baker, A., Gould, G., 2021. Socioecological mapping of barriers and enablers to smoking cessation in Indigenous Australian women during pregnancy and postpartum: A systematic review. Nicotine Tob Res.

Ramanujam, R., Hedstrom, A.K., Manouchehrinia, A., Alfredsson, L., Olsson, T., Bottai, M., Hillert, J., 2015. Effect of Smoking Cessation on Multiple Sclerosis Prognosis. JAMA Neurol 72(10), 1117-1123.

Ritchie, J., Spencer, L., O'Connor, W., 2003. Carrying out qualitative analysis. Qualitative research practice: A guide for social science students and researchers 2003, 219-262.

Royal College of Physicians, 2018. Hiding in plain sight: treating tobacco dependency in the NHS. https://www.rcplondon.ac.uk/projects/outputs/hiding-plain-sight-treating-tobacco-dependency-nhs. (Accessed 21-4-2021.

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., Jinks, C., 2018. Saturation in qualitative research: exploring its conceptualization and operationalization. Quality & quantity 52(4), 1893-1907.

Simpson, S., Jr., Tan, H., Otahal, P., Taylor, B., Ponsonby, A.L., Lucas, R.M., Blizzard, L., Valery, P.C., Lechner-Scott, J., Shaw, C., Williams, D., Ausimmune/AusLong Investigators, G., van der Mei, I., 2016.

Anxiety, depression and fatigue at 5-year review following CNS demyelination. Acta Neurol Scand 134(6), 403-413.

Srivastava, A., Thomson, S.B., 2009. Framework analysis: a qualitative methodology for applied policy research.

Stead, L.F., Buitrago, D., Preciado, N., Sanchez, G., Hartmann-Boyce, J., Lancaster, T., 2013. Physician advice for smoking cessation. Cochrane database of systematic reviews(5).

Tanasescu, R., Constantinescu, C.S., Tench, C.R., Manouchehrinia, A., 2017. Smoking cessation and the reduction of disability progression in Multiple Sclerosis: a cohort study. Nicotine Tob Res.

Tong, A., Sainsbury, P., Craig, J., 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International journal for quality in health care 19(6), 349-357.

Twyman, L., Bonevski, B., Paul, C., Bryant, J., 2014. Perceived barriers to smoking cessation in selected vulnerable groups: a systematic review of the qualitative and quantitative literature. BMJ Open 4(12), e006414.

U.S. Department of Health and Human Services, 2020. Smoking Cessation. A Report of the Surgeon General. Atlanta, GA: U.S.

US Preventive Services Task Force, 2021. Interventions for Tobacco Smoking Cessation in Adults, Including Pregnant Persons: US Preventive Services Task Force Recommendation Statement. JAMA 325(3), 265-279.

Weinberger, A.H., Kashan, R.S., Shpigel, D.M., Esan, H., Taha, F., Lee, C.J., Funk, A.P., Goodwin, R.D., 2017. Depression and cigarette smoking behavior: A critical review of population-based studies. Am J Drug Alcohol Abuse 43(4), 416-431.

Wood, B., Van Der Mei, I., Ponsonby, A.-L., Pittas, F., Quinn, S., Dwyer, T., Lucas, R., Taylor, B., 2013. Prevalence and concurrence of anxiety, depression and fatigue over time in multiple sclerosis. Multiple Sclerosis Journal 19(2), 217-224.