Improving smoking cessation support for people with multiple sclerosis: a qualitative analysis of clinicians' views and current practice

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Abstract

Introduction: Smoking is a key modifiable risk factor in multiple sclerosis (MS). MS healthcare providers have a central role informing people of the deleterious effects of smoking on MS progression and promote smoking cessation, yet there is limited information about smoking cessation and support provided by these providers. This study aimed to gain an understanding of MS healthcare providers current practices, barriers and facilitators related to providing smoking cessation support for people with MS.

Methods: A total of 13 MS nurses and 6 neurologists working in public and private MS clinics across Australia were recruited through professional networks and MS organisations. Telephone interviews were conducted, transcribed and evaluated using framework analysis.

Results: MS nurses and neurologists reported that they routinely assess smoking status of people with MS at initial appointments and less regularly also at follow-up appointments. Clinicians considered it important to provide information about smoking impact on MS health outcomes and advise to cease smoking, but the content and delivery varies. Beyond this, some clinicians offer referral for smoking cessation support, while others stated this was not their responsibility, especially in light of competing priorities. Many were unsure about referral pathways and options, requiring more information, training and resources.

Conclusion: Results of this research indicate that there is potential to improve support for MS clinicians to promote smoking cessation among people with MS. Smoking cessation support may include tailored patient resources, clinician training and stronger collaboration with smoking cessation service providers.

Introduction

Multiple sclerosis (MS) is the most common neurodegenerative disorder affecting young adults, with substantial personal and economic burden. [1-3] Modifiable risk factors that have been implicated in MS onset and progression include: cigarette smoking, body mass index, stress and some comorbidities.[4] Studies have found genes and smoking cigarettes interact, increasing the risk of MS onset,[5] and transition from clinically isolated syndrome (CIS) to clinically definite MS.[6-8] Following MS diagnosis, smoking is linked to faster and more severe disease progression[9] and smoking cessation supports brain health.[3]

Many people continue to smoke following MS diagnosis, although exact prevalence is unknown.[10] Common MS symptoms, such as depression and cognitive impairment,[11] may be barriers to successful cessation; both are linked with higher smoking relapse and may be exacerbated in the initial smoking cessation period.[12-14]

The World Health Organisation recommends clinicians actively support patients with smoking cessation and to avoid secondary smoke exposure.[15] Indeed, international consensus standards for brain-healthcare in MS recommend clinicians annually address and document lifestyle choices that may impact brain-health.[16] The Royal Australian College of General Practitioners (RACGP) smoking cessation guidelines propose a 3-step intervention Ask, Advise, Act[17, 18] (Ask, Advise, Help in Australia[19]) should be administered by healthcare providers to every person who smokes, given the evidence that advice from healthcare professionals bolsters smoking cessation efforts.[19] This three-step model, initially developed for use in primary care, has improved implementation of cessation support when utilised by oncology healthcare providers.[20]

Little is known about current practices of MS clinicians, potential barriers to assessing patients' smoking behaviour and providing cessation advice, referral and support.[9] The current study interviewed MS clinicians (neurologists and MS nurses) in Australia to gain an in-depth understanding about their knowledge and practices, available and required supports for assessing smoking and addressing smoking cessation in people with MS.

Methods

Research design

This qualitative research aimed to explore MS clinicians' perceptions of their expertise about smoking and cessation and their experience of supporting patients to quit. As recommended by Parkinson et al,[21] interview questions were derived from the literature and clinical experience, including smoking cessation models: such as the Ask, Advise Act. The semi-structured interview guide (supplementary information), data collection, interpretation and recommendations were informed with input from study investigators and a stakeholder group. Stakeholders included MS clinicians, MS community support service personnel and smoking cessation experts. All interviews were undertaken by a research assistant (AH) with minimal prior subject knowledge or personal interest. This research received approval through the University of Melbourne Human Research Ethics Committee (Ethics: 1954916.1). Research findings have been reported using the Consolidated Criteria for Reporting Qualitative Research (COREQ).[22]

Participant recruitment

Australian MS specialist neurology physicians and nurses were eligible to participate in this research. Participant recruitment was undertaken between September 2019 and Jan

2020 via relevant clinician networks, associations and events. We aimed to recruit between 10-15 clinicians. Interested clinicians contacted the research assistant (AH) and were provided with study details and an interview appointment was arranged. All participating clinicians provided informed consent prior to the interview. Participant recruitment ceased when data saturation was reached,[23, 24] as judged by the interviewer, who concurrently coded the data, in consultation with the other researchers.

Data collection

Data collection involved recording basic demographic and clinical and a semi-structured interview that lasted between 30-60 minutes. Interviews were undertaken via telephone, recorded digitally and transcribed verbatim by a professional transcription agency without further participant review or input. Telephone interviews were used to maximise access, given clinicians' limited availability[25] and to enable efficient recruitment . Transcriptions were loaded into NVivo (12 plus) for analysis.

Data analysis

Two researchers coded data in preparation for framework analysis.[26] Framework analysis combines *a priori* knowledge and assumptions, with information to gained about specific questions to include novel emergent themes from the data.[27, 28] Framework analysis was chosen because of the researchers preference to understand both diagnostic questions (i.e. investigating barriers to healthcare support for smoking cessation) and evaluative questions (i.e. investigating existing information resources). Patterns in the data were identified, coded, analysed and categorised into themes and sub-themes.[29] The refining of themes and analysis, occurred in dialogue with the research team and stakeholder group.

We reported and discussed our findings using the brief smoking cessation framework: Ask, Advise, Act.[17] Quotes provide information about whether the participant was a nurse or neurologist (Tables 2-4). We used a reporting scale to give some indication of the proportion of the sample within specific categories: A few = less than 25%, some = 25-39%, half = 40-60%, many = 61-75% and most =>75%.[30, 31] Given this is a small qualitative research study, we caution against any attempt to infer that the proportions are indicative of prevalence outside of this research sample.

Results

Demographics and participant characteristics

Participants included 13 MS nurses and 6 MS neurologists/physicians. The majority consulted with people with MS from public hospital clinics (12 nurses and 4 neurologists; Table 1). All were located in metropolitan based centres. The average interview time was 37 minutes (range 18-75 minutes). Most MS nurses reported face-to-face and telephone contact with 20 to 50 patients per week. Neurologists reported seeing between 15 and 30 patients each week, except one, who saw 2-4 per week. One clinician reported smoking 10-15 cigarettes per day, with multiple previous quit attempts.

Synthesised interview results

We discuss our findings within the Ask, Advise, Act framework, with subthemes identified for each of these topics. Supporting are provided in Tables 2 (Ask), 3 (Advise) and 4 (Act).

Ask

All neurologists and most nurses reported assessing and recording smoking status during their initial consultation with patients. Some clinicians stated that it is a routine component of the clinical assessment, while it appears more *ad hoc* for many. One nurse stated that she never assesses smoking status. It was much less common for clinicians to ask if patients were exposed to secondary smoke. Many clinicians agreed that this should be regular practice. Assessing smoking status at subsequent visits was ad-hoc and dependent on whether clinicians had prior knowledge of smoking or smelled smoke. Clinicians were generally uncomfortable routinely asking every patient at each consultation about smoking. One clinician recognised that revisiting the question about smoking was required because people may restart smoking, although most clinicians did not acknowledge this issue. Most clinicians stated that it was unusual for patients who smoke to raise the topic themselves.

All neurologists and most nurses said that it was unlikely to make a difference to their practice if smoking status was a standard item on patients' hospital records. Some nurses acknowledged that a standard record item would enabling easier identification of people who smoked and build queries into the discussion.

Advise

Advising against smoking

All clinicians agreed that they have a responsibility to inform patients about the risks of smoking. Some considered it a duty of care, whilst others considered it important but not a prioritised topic. Clinicians generally felt people with MS have more impetus to quit because of the relationship between smoking and MS progression. Many clinicians believed that most, but not all, people with MS would like to quit.

Most clinicians provided brief education to patients. Three nurses said they rarely discussed smoking with patients. All clinicians expressed high workload and competing priorities as barriers, suggesting other healthcare practitioners, particularly general practitioners (GPs), were better placed to address this issue. The infrequency of clinician contact, generally only every 6- to 12-months, was another identified barrier. However, some clinicians acknowledged that expert advice of a neurologist may give weight to promote cessation. Many clinicians stated that patients would ask what they can do to improve their chances of better disease outcomes, providing an opportunity to discuss modifiable healthy lifestyle changes, including smoking cessation.

Clinician knowledge and content of advice and resources

All clinicians were aware that smoking had a negative effect on MS disease processes, although depth of knowledge varied. Some clinicians quoted percentages and research results, others were less specific saying only that smoking made MS worse. While clinicians did not see any benefits of smoking for people with MS, some acknowledged that people with MS may believe there were benefits for stress and anxiety reduction and as a form of relaxation. One neurologist mentioned mildly improved cognition from nicotine's cholinergic properties.

The content of smoking cessation discussions varied, commonly including information about risks, impact on brain health, long-term outcomes, and cessation advice. Most clinicians reported a need for plain language written resources, such as brochures, covering the harms of smoking for people with MS to support cessation conversations. A few clinicians used MS Brain Health or Quitline resources (Quitline is a free telephone-based smoking cessation service in Australia) and many referred patients to the Quit website. Nurses in particular, identified lack of resources as the largest barrier to supporting smoking cessation.

Clinicians suggested resources should include information about how smoking effects MS onset, relapse and progression, as well as highlighting the positive benefits of quitting. Framing the message in terms of the risks of smoking and the benefits of cessation was preferred. A few clinicians suggested highlighting the potential short-term negative impact of quitting on existing MS symptoms, such as cognitive changes and anxiety, paired with support information to manage this. A few nurses suggested including MS specific information on vaping and cannabis use. The provision of online resources for younger people was suggested by one clinician.

Timing

Most clinicians felt that a discussion about smoking and the risks of MS progression should be done immediately at time of diagnosis, particularly for diagnosis of CIS, often the precursor to MS. Some acknowledged that patients are often overwhelmed with information at time of diagnosis, suggesting a follow-up discussion at approximately 6-months post-diagnosis was appropriate, with a few considering 3-to-6 months following diagnosis the ideal time to discuss smoking cessation. A few highlighted MS relapse or symptom progression as an important time to discuss cessation.

Act (Help)

Clinicians were generally understanding that quitting was a difficult process, requiring ongoing support. Commitment to actively encourage patients to stop smoking varied.

A few clinicians, mainly nurses, saw referral to smoking cessation services, discussion of quit products, and follow-up as an important aspect of their role. Neurologists, who considered it imperative to inform patients of the harms of smoking, acknowledged that their practice was more consistent with encouragement than providing active cessation support. A few clinicians stated supporting quitting attempts was not their role as they lacked the necessary expertise. None of the clinicians prescribed smoking cessation medication due to the infrequency of patient contact.

Collaborative smoking cessation support

Clinicians were generally clear that their role was to direct patients to resources, other health professionals or Quitline. Most suggested that MS nurses were better placed to support smoking cessation than neurologists, given their time constraints and priority on examination, symptom and medication management. GPs were considered better placed to provide ongoing cessation support due to their ability for regular follow-up for monitoring. Neurologists felt comfortable requesting cessation support through GP correspondence. Most clinicians recommended that patients talk with their GP about smoking cessation.

Clinicians varied in their knowledge of collaborative resources, such as smoking cessation services and MS community cessation services. Some were able to identify smoking cessation services, while others were not aware of services. Similarly, hospital-based clinicians reported variation in availability and awareness of hospital-based resources.

Many recommended Quitline and encouraged patients to make contact, seeing this as the patient’s responsibility. Few clinicians initiated a Quitline referral and some were unaware that they could refer directly to Quitline. Some reported low confidence in Quitline, as they were unaware of the processes, expertise, and privacy, therefore seeking other avenues of cessation support, such as GPs.

Consistent smoking cessation discussions and referrals were facilitated in healthcare settings with standardised institutional smoking cessation processes, such as recording, brief intervention administration and internal referral systems to access hospital smoking cessation supports, although some had long waiting lists.

Patient relationship, autonomy and readiness

While clinicians did not express concerns that discussions about cessation would impact patient rapport, most cited a preference for patient autonomy and consent in deciding whether they would like formalised support. However, a few clinicians did recommend initiating a referral, even if the person was not interested in quitting.

Tailored programs for patient-centred support

Most clinicians considered a tailored MS specific program to support smoking cessation would be more beneficial than a generic program. MS-specific training was proposed for smoking cessation counsellors to ensure programs were relevant, focused and addressed the greater barriers to cessation. Some clinicians also mentioned the importance of links to collaborative counselling and psychological expertise for people with MS to assist with broader challenges that might hinder smoking cessation, including disease control issues, adjustment to disability, stress, depression and anxiety, cognitive impairment, and social isolation. In particular, a few clinicians considered that memory deficits and impulse control cessation barriers required specialised support to be effective. Some clinicians stressed the need for more intensive education and support programs, easy English resources and the repetition of advice for people with MS who have cognitive impairments. In addition, specific supports for people with MS were suggested to assist in managing their stress, anxiety and depression, that may be initially worsened by quitting, or impact cessation sustainability.

Discussion

This qualitative study assessed current practices, barriers and facilitators to promote smoking cessation for people with MS through MS healthcare service providers. We discuss our findings within the Ask, Advise, Act framework and suggest that there are opportunities to support use of this model, originally developed and recommended for primary healthcare application,[3, 32] and adapt it for suitability to specialist MS settings. Consistent with MS clinical management guidelines, our findings identified that MS specialist healthcare providers consider it an important component of their role to promote smoking cessation. Their current practices, knowledge, and willingness to provide support, however, varied.

Ask

All clinicians stated that they ask people with MS whether they smoke when they are first seen in the clinic, but repeated asking at subsequent visits was *ad hoc*. Clinicians were resistant to continued asking about smoking if patients had no record of smoking. These findings are consistent with research showing the majority of Australian-specialist oncologists assessed and documented current smoking status and history of smoking, but were less likely to regularly ask about smoking at follow-up consultations.[20] Systematic assessment of former smokers is important given that most people who quit will relapse within the first year. Smoking relapse remains common, albeit at lower rates, years after quitting.[33-35] This highlights that smoking cessation is hard to maintain and needs to be treated as such.[36] For people with MS who experience contributing factors for smoking relapse, including stress, depression and anxiety, this may be even more significant.[33, 37] Fatigue and reduced executive capacities are also likely to be barriers and will require specific strategies.[38] Clinicians acknowledged that it was rare that patients would initiate smoking cessation conversations, supporting our previous qualitative research findings that patients want clinicians to initiate these conversations.[39]

When questioned about the value of smoking status as a standard patient-record item, most clinicians did not consider that this would change their practice, but importantly, were not opposed to this. In a busy tertiary healthcare setting, standardised recording systems are a method of identifying patients who smoke and provide a framework for team members to pursue follow-up. While inconclusive, evidence suggests that standardised electronic recording improves implementation of smoking cessation interventions, although it requires a commitment to clinician training and quality control to maximise patient value. [1740] Our research suggests there is an opportunity to improve routine assessment of smoking status through education for tertiary healthcare practitioners and by working with healthcare facility administrators to improve systemic reporting processes.

Advise

Clinicians considered it a clinical responsibility to inform patients with MS or CIS who smoke of the risks to MS outcomes. Many advised patients who were smokers of the risks to poorer MS disease outcomes, either providing encouragement or medical advice to quit. Most clinicians believed these conversations should be undertaken as soon as possible in the diagnosis process. It was also noted that patients have a lot to consider when initially diagnosed and may not be able to absorb this information while coming to terms with the diagnosis and decisions around medication. Up to 80% of information provided in medical consultation at time of diagnosis and in routine consultations is forgotten by patients, or not remembered correctly.[41] Stress and anxiety, shown to be high at time of MS diagnosis, narrows the attentional field, and highlights the need to revisit smoking conversations and support them with written patient resources.[41, 42] Some clinicians highlighted the importance of capitalising on 'teachable moments' during MS relapse to encourage smoking cessation.[43] Most clinicians reported having no written information to support smoking cessation for people with MS.

Act (Help)

Most clinicians did not actively assist patients to quit smoking beyond providing advice and encouraging to speak to their GP. Nurses were more likely, and considered more appropriate, to undertake this role. All clinicians highlighted the impact of competing priorities on their very limited time. Most stated that they considered it the role of the GP to actively assist with ongoing smoking cessation support. Some highlighted difficulties enlisting GP support if the patient did not have a regular GP or if the GP was under-resourced. Few clinicians reported actively referring to Quitline or other smoking cessation support programs and were unaware of referral options. Indeed, clinicians suggested a focus on strengthening collaborative healthcare supports between MS tertiary healthcare providers and community service organisations to improve cessation support options.

There was consensus that tailored resources would be beneficial to support smoking cessation conversations. Clinicians reported that it would be helpful to provide patients with a paper-based resource with 1) a summary of literature about the relationship of smoking and poorer outcomes in MS and 2) information about smoking cessation supports and contact options. Development of these printable resources for distribution to MS specialist clinics, neurology clinics and other MS service providers presents an opportunity to improve smoking cessation support. Clinicians would benefit from training about referral options to facilitate smoking cessation support.[44]

Depending on patient complexity, level of health literacy and self-management skills, patients may require different support approaches to empower them. Clinicians considered tailored resources and supports were needed for patients with multiple complexities (such as cognitive deficits, emotional difficulties, high levels of disability), requiring multidisciplinary input and on-going support to maintain cessation. Thus, some people with MS may require significant on-going collaborative support to achieve sustained results.[45] Clinicians suggested that smoking cessation should be prioritized in relation to other comorbidities and risks, given the focus on holistic brain health in MS, through a multidisciplinary approach.[16] Hence, the need for greater collaboration between community based and the specialist MS care teams to support long-term health outcomes, incorporating available cessation services.

Implications for practice

Given that smoking cessation does not appear to be a key clinical focus, there is a need for institutional support processes and resources within healthcare settings. The importance of supporting MS specialists in the provision of information and resources about smoking and MS is highlighted by research showing increased perceived value when shared by medical experts.[17] There is an opportunity to work with clinic administrators to improve resources available to clinicians within MS healthcare settings. Sustainability and improved efficacy in smoking cessation supports will only be achieved through increased collaboration and tailored supports for people with MS.

It is clear from our qualitative research that more can and should be done to support smoking cessation efforts through MS specialist healthcare services in Australia, and internationally. Our research indicates that a number of inexpensive processes could be improved as a priority, including the development and distribution of tailored information resources to support smoking cessation conversations and specific patient-oriented information for various MS cohorts. Other cessation initiatives may include standardised electronic smoking status prompts, reporting facilitation, clinician education and training - particularly around available quit supports, such as referral options and processes.

Limitations

As with all qualitative research, collecting in-depth and nuanced information is balanced by the limitations of small sample size. However, it provides useful preliminary information about some of the challenges and facilitators to support smoking cessation in people with MS that may be further assessed at a quantitative level.

Conclusion

The results of our qualitative study showed that Australian MS specialist clinicians agree that they have a responsibility to promote smoking cessation. Clinicians report that they commonly assess smoking status at initial consultation and often provide advice to quit. Thereafter, systematically assessing smoking status, providing information about the benefits of quitting, and referral to quit services was less common. Our research suggests that clinician training about brief interventions such as “Ask, Advise, Act”, and referral processes to available smoking cessation support services may be required. Further, MS-specific resources and services developed to support people with MS and clinician-patient discussions may facilitate smoking cessation among people with MS.

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Declaration of Conflicting Interests

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