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A qualitative study of active participation in sport and exercise for individuals with multiple sclerosis

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Abstract

Objective

The aim of this study was to explore the experience of participation in sport and exercise for individuals with multiple sclerosis (MS) with minimal disability. The objectives were to gain an understanding of key factors that influence participation in sport and exercise and to determine support required by individuals with MS to participate in their choice of sport and exercise for as long as possible.

Methods

A qualitative, descriptive study utilizing three focus groups was conducted. Data were analysed thematically aided by NVivo software. Participants were individuals with MS who had an Expanded Disability Status Scale score of 0–4, indicating full ambulation. All participants were living in northern Queensland, Australia.

Results

Sixteen individuals participated; 63% of whom regularly participated in sport or exercise. All participants viewed sport and exercise positively and identified inherent benefits of exercise. Five key themes emerged to describe the experience of participating in sport and exercise: “personally engaging with exercise,” “influencing barriers and enablers of exercise,” “sustaining independence,” “integrating exercise into lifestyle,” and “getting the balance right.” Most participants felt that advice and guidance from health professionals about the optimum mode and dose (how much and how often) of exercise was lacking.

Conclusions

Participation in sport and exercise was valued by individuals with MS with minimal disability for sustaining independence and an active lifestyle. Personalized exercise advice from health professionals was the key support identified by participants to assist them to maintain an active lifestyle for as long as possible.

Keywords: exercise; multiple sclerosis; qualitative research

Data S1: Supporting information

1 INTRODUCTION

Multiple sclerosis (MS) is typically diagnosed in young adults aged 20–40 years (Ramagopalan & Sadovnick, 2011) at a time when most are engaged in sport, family pursuits, active leisure, and employment. The challenge for individuals diagnosed with MS is to maintain a physically active lifestyle with participation in their choice of sport or exercise for as long as possible. Common exercise interventions for individuals with MS include progressive resistance training, treadmill training, and stationary cycling (Kjølhede, Vissing, & Dalgas, 2012; Latimer-Cheung et al., 2013; Swinnen et al., 2012); however, these options may not reflect the personal preferences of the individual.

Individuals with MS have been found to benefit from exercise in terms of balance, muscle strength, aerobic capacity, fatigue, and quality of life (Kjølhede et al., 2012; Latimer-Cheung, Pilutti, et al., 2013; Pilutti, Greenlee, Motl, Nickrent, & Petruzzello, 2013; Platta, Ensari, Motl, & Pilutti, 2016). Evidence of functional benefits of exercise, however, has not been overwhelming with only small but consistent benefits shown to walking (Latimer-Cheung, Pilutti, et al., 2013; Learmonth, Ensari, & Motl, 2016), with no known benefits in high-level mobility, that is, activities more advanced than independent level walking.

To date, participation in exercise and physical activity has been explored broadly across the spectrum of disability in MS with minimal reference to the mode of exercise chosen (Borkoles, Nicholls, Bell, Butterly, & Polman, 2008; Kayes, McPherson, Taylor, Schlüter, & Kolt, 2011; Stroud, Minahan, & Sabapathy, 2009). Although individuals with minimal disability from MS have the potential to participate in dynamic modes of exercise such as biking, running, and organized sports (Dlugonski, Joyce, & Motl, 2012; Kean, Oprescu, Gray, & Burkett, 2018), their experience has been largely unexplored. Understanding how to sustain high-level mobility and sporting skill requires further exploration of the experiences of individuals with MS.

Health care professionals are well placed to provide advice on sport and exercise; however, provision of this service is not always optimal or equitable (Learmonth et al., 2017a). Exploration of the experience with health care professionals, in relation to exercise advice or intervention, is an important step in identifying how best to support individuals with MS to participate in sport and exercise.

The aim of this study was to explore the experience of participation in sport and exercise for individuals with MS who have minimal disability (Expanded Disability Status Scale [EDSS] 0–4). The objectives were to gain an understanding of key factors that influence participation in sport and exercise and to determine support required by individuals with MS to participate in their choice of sport and exercise for as long as possible.

2 METHODS

2.1 Study design

A qualitative, descriptive methodology using three focus groups was conducted (Sandelowski, 2010; Stanley, 2015). This methodology was chosen to provide a rich description of the experience of participation in sport and exercise for individuals with MS (Colorafi & Evans, 2016). The methodology was situated within an interpretive paradigm as this would facilitate an understanding of the phenomenon from the perspective of those who experience it (Stanley, 2015). Interpretation of the data was shaped by the lens of the researchers in accordance with the descriptive approach (Creswell, 2009). Both researchers (M. S. and B. N.) were experienced physiotherapists in neurological rehabilitation.

2.2 Ethical approval

Ethical approval for the study was obtained from the James Cook University Human Research Ethics Committee on December 22, 2017 (Approval Number H7227). Informed written consent was received from all participants.

2.3 Participant recruitment

Participants were recruited from northern Queensland, Australia. Recruitment occurred via (a) online advertising from MS Queensland; (b) media advertising (television news and newspaper); (c) information flyer from a consultant neurologist; or (d) James Cook University website and social media. Through advertising methods, potential participants were informed that the researchers were physiotherapists and held a positive view about the value of exercise. Thirty individuals were screened via telephone for eligibility by one researcher (M. S.) and included if they had a diagnosis of MS with an EDSS levels 0–4, reflecting potential to participate in sport/exercise; were aged ≥ 18 years; were able to consent; and were living in northern Queensland. Individuals were excluded if they had an additional health condition that could impact their ability to participate in sport/exercise.

Participant selection was purposive to ensure maximum variation within individuals with MS with minimal disability in terms of age, gender, dependent children, employment, and levels of participation in sport/exercise. Participants were allocated to one of three focus groups with a maximum of eight individuals in each group to allow for potential dropout (Braun & Clarke, 2013). Comparative studies have used similar sample sizes to achieve an adequate breadth and depth of data (Malcomson, Lowe-Strong, & Dunwoody, 2008). Group allocation was based on proximity to focus group location.

2.4 Focus groups—Data collection

Face-to-face focus group interviews were conducted in two city locations in northern Queensland at James Cook University in a private room in February 2018. A videoconference focus group interview, using Zoom technology (Zoom, 2017), was conducted for participants living in rural or remote locations. Each videoconferencing participant was offered a one-to-one trial of the technology with the primary investigator, to ensure familiarity with the process prior to the focus group interview.

Interview questions were developed, piloted, and refined to explore the experience of participating in sport and exercise. Questions were open-ended in order to gain this subjective meaning (Creswell, 2009) and achieve the aims of the research. The domains and topic questions are identified in [Appendix S1](#).

Focus group discussions lasted for a duration of 59–78 min, were audio recorded, and then transcribed verbatim. Following each focus group, researchers (M. S. and B. N.) compiled a focus group summary form and team debriefing minutes.

2.5 Data analysis

Transcripts, field notes, focus group summaries, and team debriefing minutes were uploaded to NVivo qualitative analysis software, QSR International Pty Ltd. Version 11, to assist with analysis. Following reading and rereading of the dataset, descriptive coding of the data by one researcher (M. S.) enabled categorization of the data's content in a systematic fashion (Saldana, 2013). Repeating ideas were grouped under the same short title or word, creating a list of descriptive codes. Inductive thematic analysis was used to identify patterns, with similar codes brought together into preliminary themes (Braun & Clarke, 2006; Stanley, 2015). Themes were constantly refined by checking and rechecking the data, with analysis continuing until a thematic map, reflective of the data set as a whole, was created (Braun & Clarke, 2006).

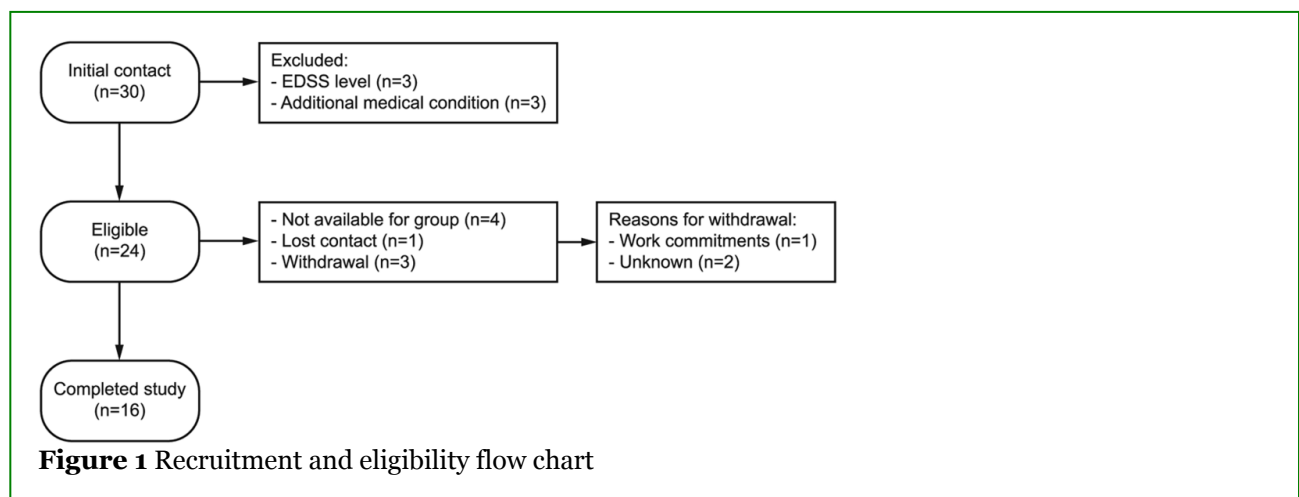
To confirm credibility and quality of the data analysis, a second researcher (B. N.) reviewed the codes and patterns from one focus group data set to check and verify, or identify discrepancies (Braun & Clarke, 2013).

In addition, member checking occurred with one participant from each group ($n = 3$) to confirm that the participant experiences or perceptions were represented appropriately (Liamputtong, 2013). Member checkers were provided with a preliminary copy of a thematic diagram via email and a follow-up telephone call to discuss the themes; no changes were required following this process. Participants chosen to member check reflected differences across the groups with respect to gender and level of engagement in sport or exercise.

3 RESULTS

3.1 Participants

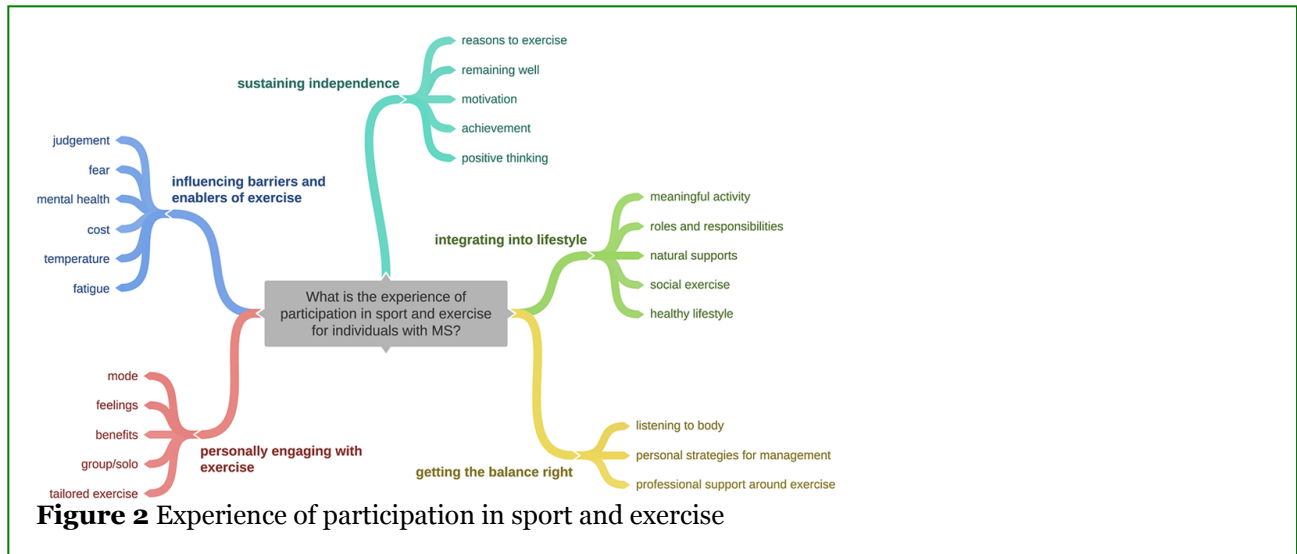
Of the 30 respondents, 24 individuals were eligible to participate. Nineteen individuals consented to participate with three dropouts on the day of the focus group interviews, leaving a total of 16 participants. Recruitment and eligibility are shown in Figure 1.



The 16 participants were predominantly female ($n = 14$) and, on average, were 41 years of age ($SD: 10.9$, range 27–61), had been diagnosed with MS for a mean of 7 years ($SD: 7$, range 0.5–20), and had an EDSS level of 1.3 ($SD: 1.3$, range 0–4). Employment status varied with six participants working/studying full time, six working/studying part time, and four not working. Fifty percent of participants had dependent children. Sixty-three percent of participants were regularly engaging in sport/exercise, where regular was defined as a minimum of one session per week.

3.2 Themes

Participation in regular sport and exercise varied with some participants engaging irregularly with exercise through to others who were exercising several times per week in such pursuits as trail running and squash that demanded high-level mobility. Even so, all participants viewed any form of exercise positively and identified inherent benefits of exercise. Five key themes emerged to describe the experience of participation in sport/exercise and factors that influenced participation: (a) personally engaging with exercise, (b) influencing barriers and enablers of exercise, (c) sustaining independence, (d) integrating exercise into lifestyle, and (e) getting the balance right. Key themes and subthemes are displayed in Figure 2.



3.2.1 Personally engaging with exercise

Each participant, according to their personal preference, engaged with and found meaning in sport or exercise. Some chose physically demanding sports that were challenging in terms of high-level mobility, skill, or cardiovascular endurance such as squash, trail running, cycling, boxing, and dancing. Others chose a gym for weights, cardiovascular training, or yoga. Walking was sometimes preferred as it could be modified easily. Participants not engaging in regular sport or structured exercise typically worked to integrate exercise into their lifestyle. Some participants chose solo and others group pursuits.

Sport and exercise were viewed as beneficial, both mentally and physically. For some, it was a stress reliever and made them feel better about themselves, whereas others reported that it made them feel stronger and less fatigued.

I feel that way when I exercise, I feel like things are gone and I do not have to worry about it so much and I do not have to think about it so much.

FG3 female participant

... the more I do the more energy I have. It's really—it helps my fatigue actually. The less I exercise the more fatigued I am.

FG1 female participant

Participants felt they lacked knowledge of the “correct” mode of exercise or sport for them and expressed the need for personalized guidance. Most participants had not been given any advice on sport or exercise from a health professional and hence, had chosen their own path based on their interests and concerns. However, participants reported agonizing over whether their exercise choice was optimal for them.

3.2.2 Influencing barriers and enablers of exercise

Participants reported some barriers to exercise that were in fact enablers for others. Fear could discourage or conversely drive exercise. Some feared that after exercise, they may not be able to walk, drive, and get back home. Fear of losing function could drive others to exercise regularly.

I always say to myself, I hope everything is going to be okay today, like nothing's going to happen to me this afternoon.

FG2 female participant

So it's very, very motivational for me to keep going, to keep on my feet basically and not lose the use of my legs.

FG3 female participant

The issue of judgement by others generated debate. Some participants felt strongly that judgement from others did not impact on their attempts at exercise, whereas others found judgement difficult to deal with. They felt judged about their lack of balance or coordination, for what was “wrong with them” and for a diagnosis of MS. Support from family members, friends, others with MS, or staff at sporting facilities with an awareness of MS was beneficial.

I think it is knowing that there is the support of not being judged ...

FG1 female participant

“Mental factors” were reported to impact on participation in sport and exercise, particularly around the time of diagnosis, when trying to come to terms with living with MS. Accepting the diagnosis was challenging and viewed as a mental hurdle that deterred them from participating in sport and exercise.

I just feel like the mental factors after diagnosis affect absolutely everything but they seriously affect your ability to exercise.

FG1 female participant

In contrast, exercise made some participants feel better by reducing their stress levels and, in turn, reducing physical symptoms. Missing out on exercise highlighted to some participants that regular exercise improved their mental health.

Heat could impact on sport and exercise with some participants finding the outdoor lifestyle and the northern Queensland weather reduced their symptoms. Others found heat fatiguing and chose to attend air conditioned gyms and swimming pools to cool off and chose cooler times in the day to exercise. Costs associated with pools and gyms were viewed as a potential barrier to sport and exercise.

3.2.3 Sustaining independence

Sustaining independence described the motivation for maintaining mobility using sport and exercise. For some, this proactive approach was underpinned by positive thinking, whereas for others, it was driven by negative past experiences. For example, some participants discussed witnessing family members or friends who had lost mobility and independence as a result of MS. Some participants feared using a wheelchair and felt that fear was driving them to participate in sport and exercise.

My motivation is—do you want to be pushed around in a wheelchair? So I get up and I get dressed and I go for a run because, I do believe I have that attitude of I must exercise, I must watch what I eat because I must stay mobile as long as I can. And I will live by that for as long as I can.

FG3 female participant

Some considered the impact that losing their mobility and independence would have on family and friends. For many of those with dependent children, their parenting role and responsibilities motivated them to exercise in order to remain well and independent and to be able to maintain their life roles, responsibilities, and lifestyle.

3.2.4 Integrating exercise into lifestyle

Participants acknowledged that exercise and sport needed to be incorporated into their lifestyle and needed to be meaningful. Responsibilities such as walking the dog or playing with children facilitated a meaningful way to incorporate exercise into the day. Work commitments could determine scheduling of exercise; however, consideration of available energy levels throughout the day was also required. For some, only a morning session would work due to fatigue levels by the end of the working day.

I'd have to work out what I need to achieve for the day

FG1 female participant

Integration of sport and exercise into personal lifestyles was often made easier by friends, family, and others through motivating and assisting them to participate in sport and exercise, for instance, through verbal encouragement, or transportation if fatigued or in difficulty after exercise. Sport and exercise were viewed as social activities by some participants and regarded with value. The commitment made to others to participate together often added motivation as participants did not want to let friends or family down by not attending. In addition, the enjoyment of the social aspect was perceived to be motivating and an important part of their lifestyle.

3.2.5 Getting the balance right

Getting the balance right was problematic, for example, how much sport or exercise is enough? Too much exercise had the potential to impact on activities for the remainder of the day or following day(s), and too little could be ineffective. Getting the balance right was determined by many through “listening to the body” and acknowledging how they were feeling, knowing how hard to push and when to back off. Some participants reported feeling “fuzzy” or “not feeling right” as a warning sign that they were doing too much. This experience could then inform future choices with respect to frequency, intensity, and mode of exercise. Variability of symptoms on a day-to-day basis was evident for many and acknowledged as a factor for consideration in integrating sport and exercise into life.

To assist with getting the balance right, participants identified a range of personal strategies for modifying the structure of their day and finding ways to integrate exercise into their lifestyle.

I just always try to think about ways I can improvise just to make it through everything.

FG1 female participant

Professional advice on sport and exercise was not readily available, with few participants having access to a physiotherapist, exercise physiologist, or personal trainer. Those that did valued advice on exercise prescription geared around living with MS from someone with knowledge in the field.

That's what I have noticed as well; a lot of gyms in the area do not have people that actually understand multiple sclerosis and what you can do and what you cannot do. Everyone's different, so many different symptoms, but yeah, no one seems to understand. It would be good for someone to actually have an idea of what it's all about.

FG2 female participant

Participants offered potential strategies to assist with participation in sport and exercise, which centred on knowledge and understanding of MS. Advice in the early stages of the disease was recommended particularly regarding suitable sport and exercise to meet their individual needs.

Personalised plans because I think everyone of us has a problem with something different.

FG1 female participant

Ideas on participation in group versus solo exercise were divided and based on personal preference. Those in favour discussed the possibility of a group for individuals with MS supported by a professional with knowledge and experience in MS and exercise. Some participants felt that a group setting with other people living with MS could allow discussion with a health professional around areas of difficulty with no judgement from others. Some did not feel the need to exercise with others with MS but felt they would value input from a professional in terms of exercise guidance.

Making the link from participant to health professional was discussed, with one group suggesting it be tied in with consultant appointments—in effect a one-stop shop where your neurological review would include assessment of your exercise needs. The use of technology, such as apps, was proposed whereby individuals could check in, view exercise options, and obtain advice from health professionals via electronic devices. Across all participants, access to a health professional with knowledge of MS and exercise prescription was seen as a way to support them to participate in sport and exercise and “get the balance right.”

4 DISCUSSION

In this study, we explored the experience of sport and exercise for individuals with minimal disability from MS. Participants were generally engaged in sport and exercise and worked to integrate exercise into their lifestyle. A strong drive to sustain independence could enable participation in sport and exercise. Other influencing factors of fear, temperature, and fatigue could either impede or enable participation. Concerns were expressed by participants about getting the balance right with respect to exercise mode and dose (how much, how often, and how intense?). To address this concern, participants expressed the need for personalized exercise advice from health professionals with knowledge of MS and exercise. However, access to a health professional with expertise in this area was uncommon.

Individuals with minimal disability from MS were choosing to participate in a variety of challenging sports and exercise modes that demand high-level mobility and skill. Challenging pursuits such as trail running and squash demand a higher level of mobility than many exercise interventions that have previously been assessed with individuals with MS, for example, treadmill walking and progressive resistance training (Kjølhede et al.,

2012; Swinnen et al., 2012). This finding indicates that the challenge and dynamic nature of exercise offered to individuals with MS (EDSS 0–4) needs to be greater than it is currently. Personal choice is important, and advice needs to be tailored to the individual to sustain or improve participation in their chosen mode of sport or exercise. Exploration of different modes of exercise is required to ensure we improve and maximize beneficial outcomes (Motl & Sandroff, 2015). High-level mobility outcomes such as running, jumping, or sporting achievement are not typically assessed in this population but are necessary to identify whether potential is reached. Ultimately, it is important to determine whether challenging sport or exercise interventions enable individuals with MS to remain active and independent for longer.

Minimum physical activity guidelines for individuals with mild to moderate MS disability are available (Latimer-Cheung et al., 2013); however, what is not known is the optimum exercise dose for maximum gain. “Listening to the body” has been used by participants in this current study and in previous studies (Smith, Hale, Olson, & Schneiders, 2009) to guide the exercise limits. By doing so, the exercise dose may be below the level that provides maximum benefit (Christensen, Brincks, Schnieber, & Soerensen, 2016; Kayes et al., 2011; Latimer-Cheung, Martin Ginis, et al., 2013) or conversely, for those who “push the boundary,” could exacerbate symptoms. Assistance with interpreting symptoms during or after exercise is required to determine whether the response is MS or exercise related and when to push on or back off. To identify exercise limits, examination of the physiological changes associated with high-level mobility sport and exercise in MS is required. Previous research has demonstrated significant but small reductions in fatigue in response to exercise training (Pilutti et al., 2013); however, the optimum mode and dose of exercise are yet to be identified. In addition, small changes in muscular and moderate changes in cardiovascular fitness have been identified with exercise training (Platta et al., 2016). In these studies, the mode of exercise investigated has typically centred around use of stationary aerobic and strength training equipment such as progressive resistance weights, cycle, or arm ergometers. Active lifestyles involving sports and other activities that require dynamic skilled movement (e.g., running, squash, or outdoor cycling) have yet to be explored.

Challenging individuals with MS in sporting and exercise activities requires risk assessment. There is a potential risk of doing too much, yet conversely, too little can have negative consequences for mobility and disability (Motl, 2010). General exercise training has not been associated with any increase in risk of relapse or adverse events (Pilutti, Platta, Motl, & Latimer-Cheung, 2014); however, the safety of participation in higher level activities has not been examined. Safety of different exercise modes, particularly those that require a high-level of mobility, also needs exploration in order to further inform choices for people with MS.

Barriers to exercise were shared across participants regardless of whether they exercised regularly or not. Personal factors such as fear or judgement could halt or impeded exercise with the impact dependent on the individual. Support from health professionals is required to address these factors and enable exercise participation. Behavioural management strategies and education have previously been identified as a requirement in this process (Christensen et al., 2016; Learmonth & Motl, 2016).

Participants in this research wanted information and advice from health professionals with knowledge in MS and exercise, which is consistent with other studies (Hale, Smith, Mulligan, & Treharne, 2012; Learmonth et al., 2017a). However, few participants had received any such advice or intervention. Patient-provider consultations, paper, and electronic media have been previously reported to be preferred formats for exercise information amongst those with MS (Learmonth et al., 2017b). Participants in the current study suggested a one-stop shop (neurological review including assessment of exercise) and use of electronic technology such as apps. Use of an app could connect the individual with MS and provider electronically, charting progress, particularly for those individuals who live rurally and remotely and have reduced access to rehabilitation services (Foster, Allen, & Fleming, 2015). Longitudinal charting of exercise and related outcomes, via an app, could enable decision making and hence aid integration of sport and exercise into a healthy lifestyle. In addition, the use of an app could enable the personalization of exercise advice requested by participants and is a potential area for future development.

Some limitations were evident in this study. Participants were recruited from northern Queensland from regional, rural, or remote locations. Consistent with the intent of qualitative research, findings may not be generalizable across states, or internationally, due to differences in health care services, facilities, access, and

environmental considerations. However, given the variation in lifestyle between study participants, the study offers a broad perspective on the topic, and some of the findings may be transferrable to other contexts. The majority of participants were female ($n = 14$) reflecting the greater female predominance of MS (Ribbons, Lea, Tiedeman, Mackenzie, & Lechner-Scott, 2017). To ensure a male viewpoint was appropriately considered; member checking with one male participant was purposely employed (Braun & Clarke, 2013; Stanley, 2015). The authors acknowledge that there may have been volunteer bias with participants reporting exercise as beneficial. Efforts to reduce this included recruiting participants who did and did not regularly participate in exercise.

In conclusion, this study examined the experience of sport and exercise for individuals with minimal disability from MS. Participants were capable of undertaking challenging sport or exercise; the benefits of which have not been previously explored with this population. The optimum sport or exercise mode and dose are not known nor are the risks associated with high-level mobility sport and exercise. To “get the balance right,” individuals with MS recommended novel ways to gain personalized sport and exercise advice from health professionals with knowledge of MS.

5 IMPLICATIONS FOR PHYSIOTHERAPY PRACTICE

Physiotherapists need to support individuals with MS who have minimal disability to participate in sport and exercise as part of an active lifestyle. Through personalized assessment and exercise advice, physiotherapists can help people with MS to get the balance right between too much and too little exercise. Further research on sport and exercise for people with MS is required to provide evidence upon which physiotherapists can base their clinical decisions.

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CONFLICT OF INTEREST

The authors declare they have no conflict of interest.

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