

Background

Physical activity (PA) is known to be beneficial for people with multiple sclerosis outside the relapse period¹, while little is known about how people experience PA during a relapse². This study investigates the experiences of adults with relapsing remitting multiple sclerosis (RRMS) engaging with PA during a relapse, identifying barriers and facilitators.

Methods

The study adopted a qualitative exploratory design, following an interpretivist approach. Participants were purposively sampled from a specialist relapse clinic. Semi-structured interviews were conducted with people with RRMS who experienced a relapse in the preceding four months. Data was audio-recorded, transcribed verbatim and analysed inductively using Framework Analysis³.

Results

Fifteen participants (11 female) with RRMS were interviewed. There was a range of demographic characteristics, current PA levels and level of disability. Participants reported a range of symptoms as a result of their recent relapses, with the most frequently reported being leg weakness (73%), Fatigue (67%) and sensory symptoms (67%). Inductive analysis resulted in the emergence of four themes which are described here and supported with anonymised quotes.

The road to recovery

This theme reflects how participants experienced their relapse and how this affected their ability to engage with PA. Participants varied in their view of how much PA they could do during their recent relapse, partially due to their varied symptoms and severity of relapse but also due to different ways people approached their recovery.

'It's also the motivation to me of knowing, that you can't lie around for too long. I'm not going to let myself, because then I think you know all the muscles, I'm not helping in that way... I've got to start managing my MS.' (Dorothy)

'I'm just going and listening to my body I guess. As I said trying not to push my body too much so I'm building it up... so I'm listening to my body really.' (Jane)

'I can't find anything that works because I'm always so tired and I don't have the energy. I think it's just weakness I think right now so that's why I don't do any activities right now.' (Jasmin)

The fear of making things worse

This theme explores the conflicted feelings people had about engaging with PA during their relapse. They were aware of the benefits of PA but were also fearful of making things worse, which served as a barrier to being active. Fears included exacerbating symptoms, increasing risk of falls, causing another relapse and others becoming aware of their disability when they exercised.

'I've just been resting basically and that's all I've been doing. The fear of causing any more problems... I'd end [up] rather limping or holding onto something to compensate for it. So, I thought the best thing to do was just to rest it this time.' (Ish)

'If I go to the gym people are going to think is that [Jasmin]? Because to look at me, to look at me now, you just think..., but once I try and do things you can see that I really can't do much. That's a little bit embarrassing.' (Jasmin)

'I was just worried that it [PA] might cause another relapse or you know, it will make my immune system low... If I'm low, I'm just worried if I'm doing something that could have an adverse effect then I'm not going to bother doing it.' (Stacey)

Am I the expert?

This theme highlights how people had different ways of coping with their relapse. Some people were confident with accessing support and directing their recovery. However, others had difficulty seeking support, perhaps in part due to low mood. This left them feeling isolated and vulnerable and led to them being less physically active.

'I'm just guessing what the right balance is of how much physical activity I should be doing and perhaps if I had a bit more guidance. It could be that I'm wrong in my assumption and maybe I should be doing less or maybe I should be doing more. So, I'm just playing it by ear, you know thinking what I think is the best thing to do really. I'm not sure really if it's the right thing though.' (Jane)

'So you can learn a lot yourself online. You don't have to pay your personal trainer or whatever. You can do your own research. That's quite empowering.' (Rachel)

'What made it difficult was the fact that the recovery process, it's not knowing what to do.' (Ish)

Can I make a difference to my MS?

All the participants spoke of the benefits of PA when recovering from their relapse. They were aware that PA might help build up their strength, had a positive impact on their mood and boosted their self-esteem. Despite this, some participants found it hard to be active due to fatigue and low mood.

'I noticed... when I have [been rowing] my walk to the tube at the end of the day is easier... that's when I notice it most actually, it's the walk. Walking at the end of the day, I just feel a bit stronger with a bit more energy.' (Daniel)

'You start to feel like you don't want to do anything. You just don't feel like going out and you look outside and you think I could go for a walk but you think I don't want to go for a walk, you just want to sit indoors vegetating.' (Ish)

'Regardless of how I feel, I feel a lot better afterwards, even mood wise I feel a lot better' (Fatima)

Conclusions

- Key barriers to PA included: feeling unwell, physical limitations, concerns about making their condition worse, worry about others recognising they had a disability and lack of professional support.
- Key facilitators of PA included: awareness of the benefits of PA, access to exercise resources, adequate support and time and PA pitched at the right level for a sense of achievement.
- Further research is needed into the safety of PA during a relapse and identification of the optimum way and most appropriate time to support people returning to PA following a relapse.