



# The lived experience of physical exertion for persons living with advanced multiple sclerosis: piecing together the puzzle, to seek a sense of normality in the unpredictable body

## Background and aim

Persons living with MS (plwMS) need to be constantly adapting to new styles of being\*. Exercise and physical activity are safe and effective means of maintaining function, optimising quality of life and coping with the unpredictability of the condition but plwMS remain less physically active than the age matched population\*\*. Health Care Professionals (HCP) have an importance role in guiding plwMS to be more active, however literature suggests discrepancy between HCP prescription and adherence by plwMS\*\*\*. This inquiry aimed to explore the lived experience of physical exertion from the perspective of persons living with advanced MS.

## Method

An interpretive phenomenological approach was adopted to explore the meaning and structure of physical exertion, as it manifests through participants' lived experiences. Semi-structured interviews were conducted online using Microsoft Teams. Interviews were audio recorded, then transcribed verbatim, and pseudonyms were used to protect participant identity and confidentiality. Ethical approval was received for the study from the University of Brighton's Ethics and Governance Committee.

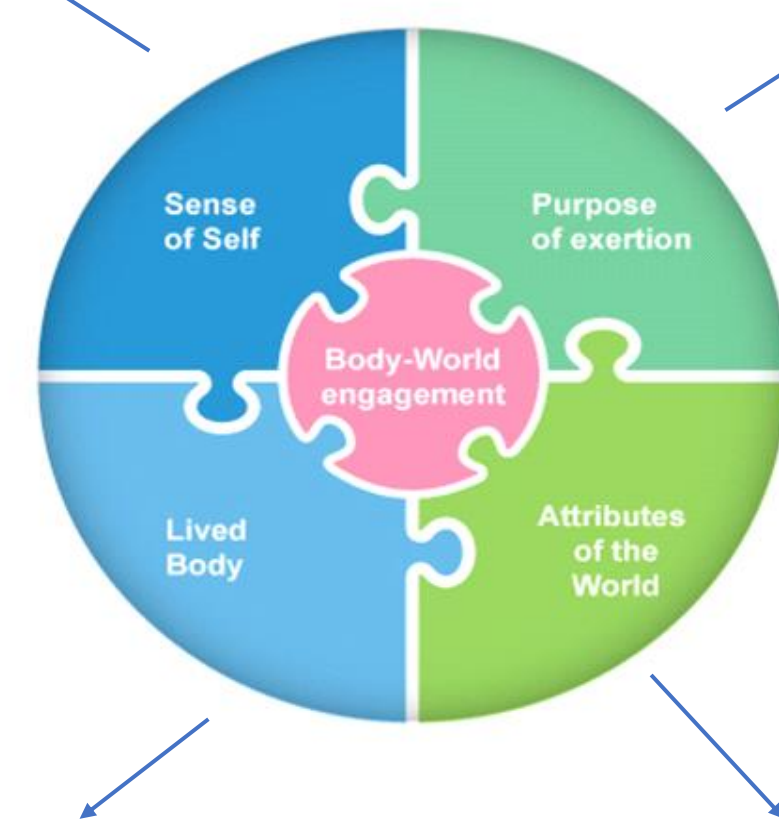
8 participants were purposefully recruited from an MS Therapy Centre in England. The participants, 2 men and 6 women, had a mean time of 16.25 years (range 10-25 years) since MS diagnosis and self-reported inability to walk more than 20 metres with an aid (3 participants were full time wheelchair users). A sequential, stepped approach was taken to analysis, initially exploring accounts individually and then across participants, to find connections and illuminate patterns and contradictions enabling synthesis and integrate of themes. The principal researcher sought to maintain an open-minded approach to analysis but acknowledged their role in interpretation and explication of meaning.

## Results

Participants conveyed their lived experiences of physical exertion as an opportunity to **influence their connection with the world through their bodies**. Four subthemes: *Sense of Self*, *Lived Body*, *Attributes of the World* and *Purpose of exertion* and a core (master) theme, *Body-World engagement* were identified, that described the structure, as a 'physical exertion jigsaw'. The 2 participant stories illuminate the relationship between jigsaw themes and the meaning of physical exertion to them.

The Physical exertion jigsaw puzzle, illuminates the intertwined relationship between the subthemes and core master theme, where the dovetails between jigsaw pieces imply a sense of connection

- Physical exertion as an influential effect on identity and agency
- Experience of exertion was influenced by self-beliefs
- Sense of loss at being 'upright'
- Desire to be 'normal'



- Exertion illuminated a bodily consciousness
- Evoked a critical appraisal of the physical body
- Bodies were unpredictable
- Exertion could evoke a sense of vulnerability and need to learn for self-preservation

- Physical exertion as a movement of the body within the world
- Spectrum of activity
- Purpose shaped expectations and self-beliefs
- Opportunity to take back control
- ADLs as sources of frustration and anxiety

- Influential effect on the adhesive of the connection with the world
- Double edged- both enhancing and disempowering
- Included assistive equipment, other people, the environment and the structure of activity

### David's story; The energy tank

'Some days the energy is just gone. Getting out of bed is hard work. I feel worn out on waking and I need to sit down to rest and recover after getting dressed. Standing up is hard, I am constantly moving to try and stay upright. My bad leg just doesn't want to go, and the effort makes my breathing heavy and I have to sit down and recover. I try to do some work in the garden. I can't stand up but sitting down I can't maneuver things. Then all of a sudden, I run out of energy, the tank goes to negative. I'm left feeling useless with nothing left in me, I have knackered myself. There's no use crying about it, I just have to sit and rest for 5 minutes and then I see if I can carry on. It makes me feel fed up, annoyed, but I just have to cope with it.'

I like going to the gym. When I work out in the gym, I feel a 'good worn outness', I've done something normal, like everyone else. It's not the same as the fatigue I get at home. It's like when you do any form of cardiovascular exercise and you push yourself, a physical knackeredness, a tired feeling. I like doing group sessions with a coach. I really push myself, something I never do outside the gym. I think when you are exercising by yourself it is very easy to give up but, in a team, there's a herd feeling of being part of something and it is encouraging. We are all putting ourselves through it and pushing each other. The interval sessions are hard work but there is always a stopping point, when you can rest and recover. That is important. I come out of the gym feeling drained but it makes me feel normal.'

### Anne's story; underestimating the effort

'It is very easy to underestimate the effort of everyday activity. At home I push myself in my wheelchair, it's tough, my limbs feel like they have got weights tied onto them, making everything harder. Then someone leaves their shoes out, or a door closed, and the obstacles make it harder. I get so angry, the frustration uses up energy and it's like a catalogue of events, that ends in energy wipe out. Sometimes I've sat for quarter of an hour looking at a cup, just to focus my mind and summon the energy to pick it up to drink. You wouldn't believe how much energy it takes to concentrate on my fingers. It sounds pathetic but it is so incredibly challenging, it's mind over matter. I will be determined to do it, and when I get my fingers to move, it's a lovely feeling.'

I like going to the centre and standing in a frame. I know that I am using energy, I feel tired when I get home but standing feels like I am putting energy into my body, to hold it in position. Standing up feels like I have re-joined the 'normal' world. I'm doing something that everyone else takes for granted. Being upright and talking with friends is exciting and the time flies. Even if it feels harder than normal, I won't get down. I'm too stubborn, I enjoy it too much! I'll recover at home in the chair. I'll close my eyes and before I know it, I've fallen asleep for half an hour! Rested and ready to re-engage.'

## Conclusion

This phenomenological inquiry has provided a more in-depth, nuanced, understanding of the day-to-day realities of physical exertion for person living with advanced MS, that could be used to influence understanding and practice. It encourages HCP to consider:

- Physical exertion as an opportunity, but also threat to person's sense of wellbeing
- The impact of self-beliefs, past experiences, and the importance for participants to appear 'normal'
- The wider context of the body in physical exertion, beyond the object that can or cannot move, but one that is embodied with person's sense of Self
- Participants were acutely aware of how their bodies failed to meet their expectations and those of society. HCP are encouraged to consider how they portray the body in their language, that could heighten their sense of failure
- The impact of the physical and emotional toil of activities of daily living

By taking time to explore person's beliefs, past experiences and identity, HCP can begin to understand the body from the perspective that encapsulates person's wishes, dreams, and hopes. In doing so they can begin to understand how connections between the components of the physical exertion jigsaw puzzle can be strengthened.

### References

- \* Wilski M, Tasiemski T. Meaning of self in multiple sclerosis: Implications for treatment and rehabilitation. *Advances in Experimental Medicine and Biology*. 2017;95(8):43-55.  
 \*\* Learmonth Y, Rice I, Ostler T. Perspectives on Physical Activity Among People with Multiple Sclerosis Who Are Wheelchair Users: Informing the Design of Future Interventions. *International Journal of MS Care*. 2015;17(3):109-119.  
 \*\*\*Stennett A, De Souza L, Norris M. A qualitative exploration of physiotherapists' perceptions about exercise and physical activity: reflections on the results from a Delphi Study', *Disability and Rehabilitation*, 2020;42(22):3142-3151.