

Understanding leisure-time physical activity: Voices of people with MS who have moderate to severe disability and their family caregivers

Afolasade Fakolade, Julie Lamarre, Amy Latimer-Cheung, Trisha Parsons & Marcia Finlayson

Queen's University, Kingston, Canada.



INTRODUCTION

- Regular participation in leisure-time physical activity is beneficial to all aspects of health^{1,2}.
- 78% of individuals with MS are physically inactive. Family caregivers may have limited time and opportunity to engage in leisure-time physical activity^{3,4}.
- For researchers and clinicians to effectively promote physical activity among caregiver-care recipient dyads affected by MS, a comprehensive understanding of physical activity experiences among these groups is necessary.

Purpose

- To explore joint perceptions of people with moderate to severe MS and their family caregivers about leisure-time physical activity and directions for intervention.

METHODS

- A qualitative focus group study.

Inclusion & Exclusion Criteria

- Inclusion criteria for people with MS:** Diagnosis of MS, ≥18 years old, PDDS score between 3 (moderate disability) and 6 (bilateral support required).
- Inclusion criteria for family caregivers:** ≥18 years old and providing at least 45mins/day of support to a person with MS who has a PDDS score between 3 (moderate disability) to 6 (bilateral support required).
- Exclusion criteria for both people with MS and family caregivers:** Inability to tolerate a 90 minute discussion completed entirely in English and inability or unwillingness to arrange own transportation.

Data Collection

- Thirty-five participants took part in one of six focus groups conducted across three sites in Ontario.

DATA ANALYSIS

- Qualitative analysis using a constant comparative approach to arrive at a descriptive thematic categorization of data.

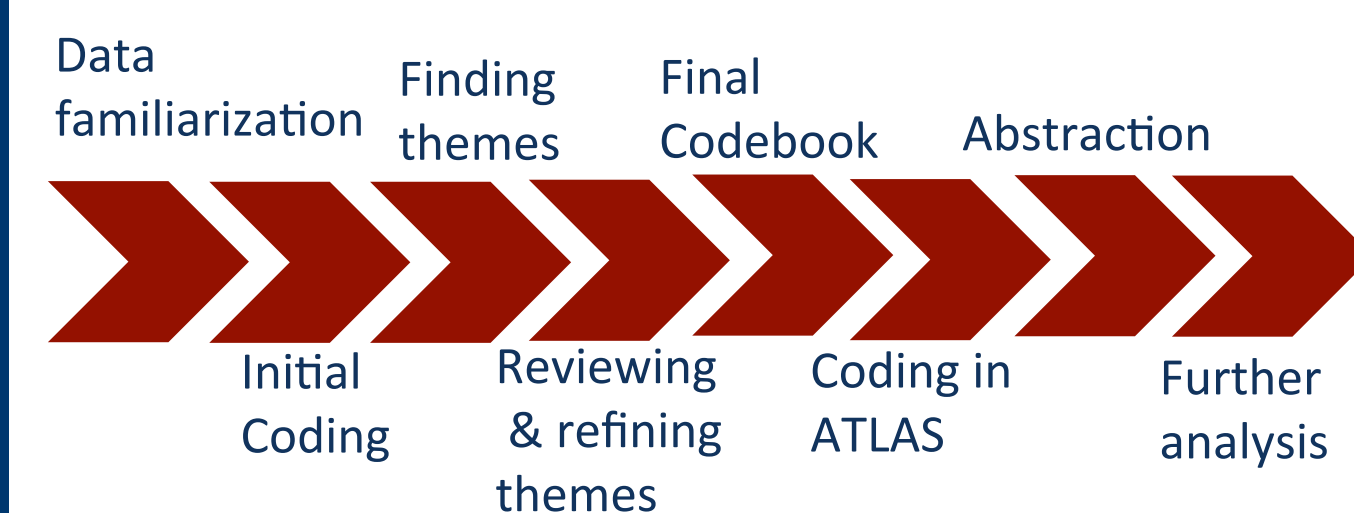


Figure 1: Key phases of the data analysis process

PARTICIPANTS

Table 1: Characteristics of People with MS (N= 23)

| | Mean (SD) |
|-----------------------------|--------------|
| Age | 54.6(9.8) |
| Disease duration (in years) | 14.7(9) |
| PDDS | 4.7(0.9) |
| | N (%) |
| Gender | |
| Female | 16(69.6) |
| Marital Status | |
| Married | 16(69.6) |
| Separated | 4(17.4) |
| Type of MS | |
| Relapsing Remitting | 11 (47.8) |
| Employment status | |
| Unable to work/Disability | 16 (69.6) |

Table 2: Characteristics of Family Caregivers (N= 12)

| | Mean (SD) |
|---------------------------------------|--------------|
| Age | 57(13.8) |
| Years of caregiving | 10.9(7) |
| | N (%) |
| Gender | |
| Female | 6(50) |
| Relationship to person with MS | |
| Spouse | 8(66.7) |
| Non-spouse | 4(33.3) |
| Employment status | |
| Retired | 6(50) |
| Not employed | 3(25) |
| Full time (≥ 40hrs/wk) | 2(16.7) |

FINDINGS

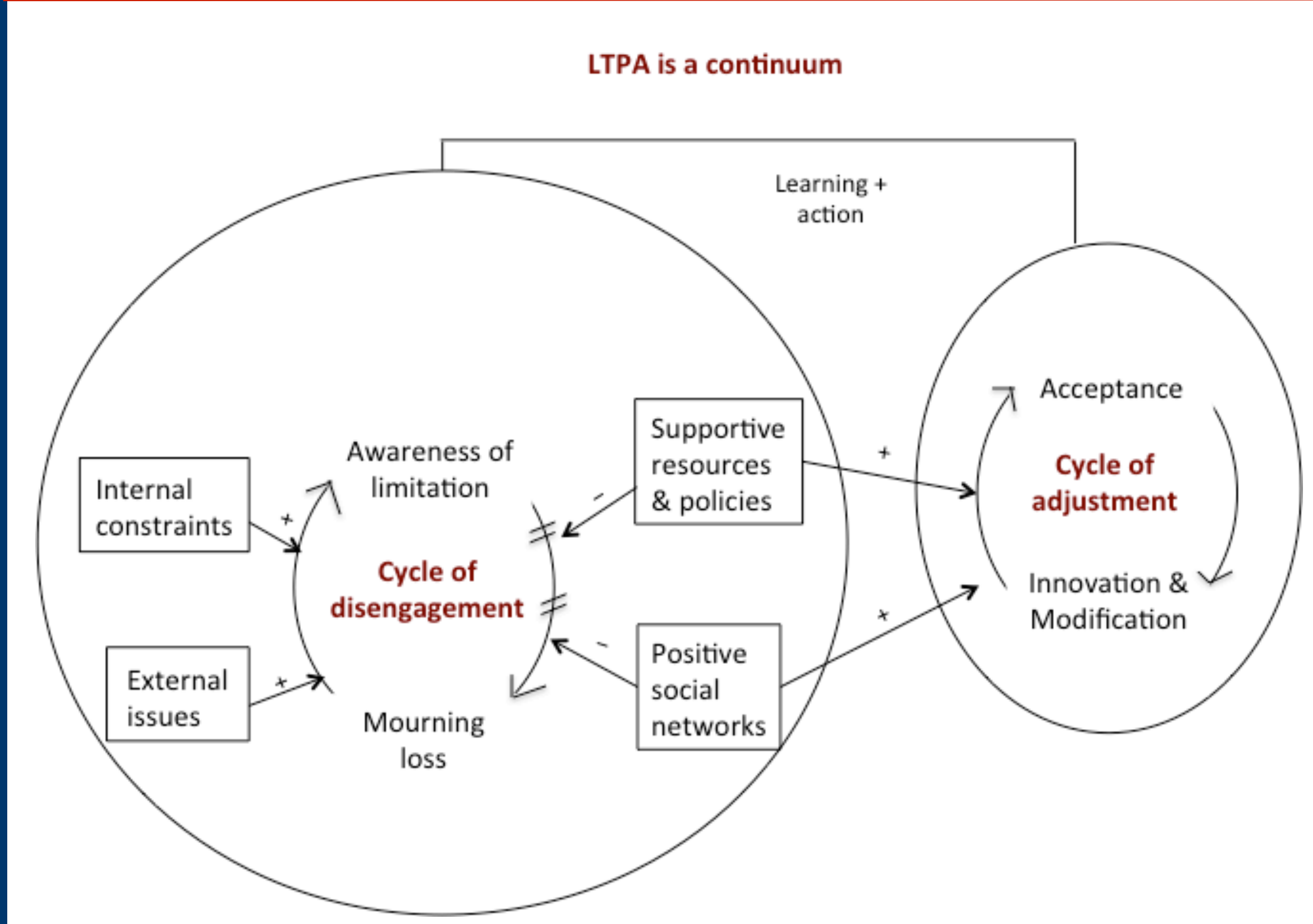


Figure 2: Graphic depiction of study themes and the relationship between themes

THEMES & SUB-THEMES

- Three broad themes were identified: cycle of disengagement, cycle of adjustment & leisure-time physical activity is a continuum.

Theme 1: Cycle of disengagement

- More apparent in the stories shared by dyads currently participating in little or no physical activity.
- Awareness of limitations** – reflections on how physical limitations experienced by people with MS restricted the dyads' participation in physical activity.

"there are chores that need to be done around the house and things that she [person with MS] used to do before that I have now taken over and that's offset some things I used to enjoy. I used to go out for walks and hikes but I'm now sticking around a little bit more to do more around the house" (Bob, family caregiver).
- Mourning loss** – frustration when comparing previous and current abilities & sadness at loss of freedom and independence.

"...when I think of it [physical activity], it's such a loss because I think about what I used to do and what I would like to do... I used to dance and I used to teach fitness. I'm still grieving that loss of not being able to do that" (Abby, person with MS).

Drivers & inhibitors

- Some dyads remained in the cycle of disengagement because of **internal constraints** and **external issues** such as lack of knowledge and skill, presence of other comorbid conditions or negative feedback from others.
- When **supportive resources & policies** and **positive social networks** were available, the dyads were able to break out of the cycle of disengagement and move towards the cycle of adjustment.

Theme 2: Cycle of adjustment

- This theme was captured more in the stories shared by dyads starting to engage in some physical activity.
- Acceptance** – The dyads in this cycle had accepted the reality of having MS and made adjustments to incorporate physical activity into their daily routines.

"like I mean I'll do as much as I can for the first 2 hours in the morning... whether it's cleaning the kitchen or whether it's up and down the stairs with laundry. And that's not every morning. But that's my exercise. And then I'll sit. And if I have to sit in my chair for 2 hours that's okay. And so I just have learned, which was really difficult, just to accept that..." (Elena, person with MS).
- Innovation & Modification** – The dyads were working collaboratively to redefine what physical activity meant to them. They also reported the need to shift expectations on type of activity to engage in as well as mechanism of engagement.

"... that was very difficult to handle in the beginning. But it isn't now. My husband helped me with that. I've got it [MS]. There's nothing I can do to change it. But I can work with it. And I did. And with the support of my husband, coming up with ideas about what we could do for physical activity. And that worked amazing" (Cathy, person with MS).

Theme 3: Leisure-time physical activity is a continuum

- This theme captured the understanding of the dyads who had successfully moved through the cycles of disengagement and adjustment and were now engaging in physical activity.
- Through the process of moving through the cycles came the realization that physical activity is not restricted to structured, planned & supervised activity but also includes leisure activity, activities performed during everyday occupations, household activities etc.

... It [physical activity] could be running, jogging, or you know walking to work. Just anything I guess that kind of gets the body moving and gets your blood flowing and heart pumping and makes you feel good (Bob, family caregiver).

DISCUSSION

- Ongoing interest in promoting physical activity among people with MS, but little is known about the perspective of dyads affected by moderate to severe MS.
- Physical activity is an interpersonal experience with caregivers and care-recipients sharing similar struggles and frustrations, suggesting that mutuality is an important construct to consider among MS dyads.
- The dyads understand the need for adjustments and collaboratively seek support to be able to successfully increase physical activity.
- Clinicians need to understand how to intervene and provide support for the dyads to make these adjustments.
- Findings are congruent with self-determination theory, which may make it valuable in designing physical activity interventions that are effective and mutually beneficial to the needs of both caregivers and care recipients affected with moderate to severe MS.

LIMITATIONS

- It was not always possible to recruit both members of a dyad, which may have resulted in a "selection effect" where the caregivers who participated in the focus groups may be different from those who chose not participate.

CONCLUSION

- Findings indicate the need for both caregivers and care-recipients to adapt to the broad effect of MS on their lives and work together to find options to engage in physical activity.
- Clinicians and researchers need to start adopting an integrative approach that addresses caregiver-care recipient dyads as a focus for physical activity promotion interventions.

REFERENCES

- (1) Rimmer & Marques. *The Lancet*, 2012; 380: 193-5; (2) Meneguci et al. *Journal of Physical Activity & Health*, 2015; 12(11): 1513-19; (3) Latimer-Cheung et al. *Arch Phys Med Rehabil*. 2013; 94: 1829-36; (4) Shereman et al. *Mult Scler*. 2007; 13(2): 239-49
- Funding: AF received research funding from the Canadian Disability Participation Project supported by the Social Sciences and Humanities Research Council of Canada Grant # 895-2013-1021 (to AL-C). This work was also supported through a Waugh Family Doctoral Studentship Award from the Multiple Sclerosis Society of Canada to AF.

Acknowledgement: Thank you to Dr. S. Morrow for recruitment assistance, Ms. D. Bowman for recruitment assistance and co-facilitating focus groups & Ms. J. Petrin & for co-facilitating focus groups.