Longitudinal and idiographic methods of developing and evaluating tailored psychological interventions for people with MS: findings from a pilot study and future directions

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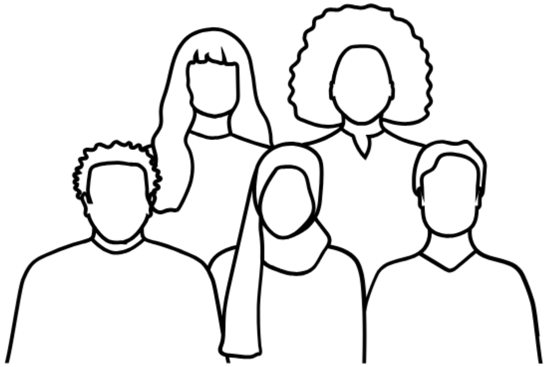
There is no such thing as a typical MS patient

Heterogeneity and impact on self



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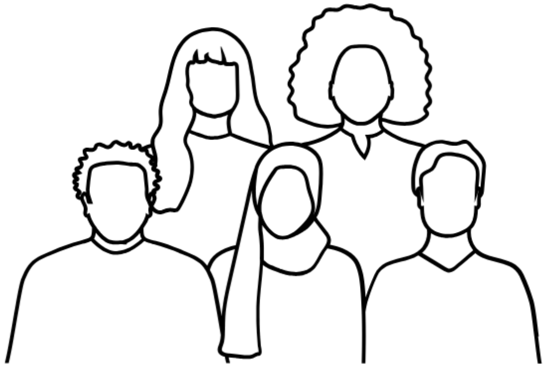

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Mental health support is one of the most significant unaddressed need for people affected by MS

Psychological interventions

Psychological interventions

CBT

Psychological interventions

CBT

ACT

Psychological interventions

CBT

ACT

MBI

Are the measures appropriate?

Are the designs appropriate?

Are the interventions appropriate?

People with MS needs and preferences

- Tailored and flexible interventions
- More than one modality
- Adaptations
- Good knowledge of MS

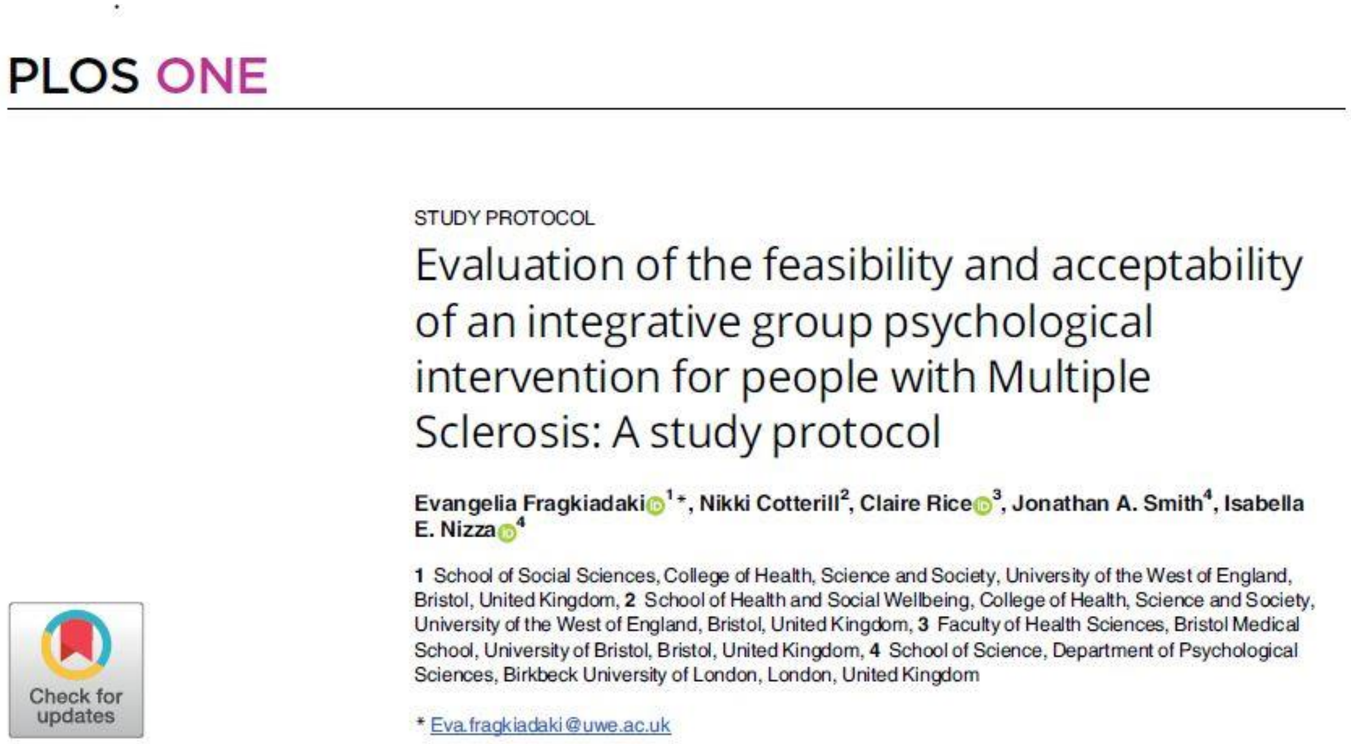
People with MS needs and preferences

Longitudinal, qualitative designs to understand change beyond standardised measures

- Tailored and flexible interventions
- More than one modality
- Adaptations
- Good knowledge of MS

Our study

- Feasibility and acceptability study of MyMS-Ally integrative group intervention
- Mixed-methods longitudinal design



PLOS ONE

STUDY PROTOCOL

Evaluation of the feasibility and acceptability of an integrative group psychological intervention for people with Multiple Sclerosis: A study protocol

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Check for updates

MyMS-Ally

Sessions	**Examples of techniques**
Week 1: What do emotions have to do with it?	• Keep a journal • Psychoeducation– mind/body connection
Week 2: What is MS? Who is my MS?	• Relating to my MS – create a narrative, a story
Week 3: The mindful body with MS	• Relating to the body with MS • Representations of disability
Week 4: The difficult emotions in the journey	• CBT exploration of thoughts • Working with these thoughts (ACT, CBT)
Week 5: “Us and Them”	• Building and redefining relationships after the MS diagnosis
Week 6: Every day with MS is a day to celebrate	• Living the new life with MS: everyday problem solving and coping mechanisms
Week 7: We are not only MS	• Engaging my MS in discussion: gestalt and narrative techniques
Week 8: What I am taking with me	• Reflections on endings and techniques

Recruitment

- NHS and community
- 5 women, 34-59, RRMS, d: 9-22 years
- MyMS-Ally intervention facilitated online by trained therapist

Qualitative Data Collection (3 times)

- Collection, analysis and final presentation of data draws on guidelines of **Longitudinal Interpretative Phenomenological Analysis (LIPA)**

Quantitative Data Collection (4 times)

- Satisfaction with Life Scale (SWLS)
- Hospital Anxiety and Depression Scale (HADS)
- Emotion Regulation Questionnaire (ERQ)

Trajectories of change

Theme	Invisible VS visible disability	Participant	Trajectory description
Navigating the complicated relationship with their MS: from rejecting to accepting vulnerability	Invisible disability	Cathy	From pretending not to have MS and perceiving disability as an ending to imagining life with visible symptoms without fear
		Fedra	From fighting her MS with a strong body to developing awareness and a kinder attitude towards how MS determined who she was
		Lisa	From avoidance and maintaining control to giving in and coping with fear of disability
	Visible disability	Julia	From being judgemental about her MS to being open and self-assured with it
		Kate	From resisting being dependent on others because of MS to accepting help

Cathy's trajectory: From pretending not to have MS and perceiving disability as an ending to imagining life with visible symptoms without fear

Time 1: Baseline	Time 2: Post-intervention	Time 3: Follow-up
"what's the point? I'm gonna end up in a wheelchair pretty soon. And that's it." *"pretend that I'm OK even though I have it (MS)".*	*"I'm used to talking about it but more like, umm, outside of me in a way, like not really talking about my experience, but more like the person with MS experience, and that's a very different thing, it's very confronting".* *"but I I changed my perspective when people using a assistive device for like, well like a wheelchair (...)I just kind of like made me realize maybe I'm less afraid of when that happens."*	*"So I didn't, like, feel like a poser a lot, you know, like, yeah, but, you know, there's something wrong [...] It (discussing new symptoms with PT) just validated that there's something wrong".* *"I wonder what it would be like if people just naturally like saw this (MS symptoms) so that I didn't have to like. I feel like I'm hiding something all the time, in a way."*

Fedra's trajectory: From fighting her MS with a strong body to developing awareness and a kinder attitude towards how MS determined who she was

Time 1: Baseline	Time 2: Post-intervention	Time 3: Follow-up
"and it (MS) can live with me while I do my thing." *"I'm gonna work on making myself, fitter and stronger. Ignore sensations and that worked."*	*"I don't know how I'd feel about doing it (specific activity) anyway had I never been diagnosed with MS. So it's like a funny one. Like obviously with this has brought awareness to me. I don't know if I'd have that determination."* *"talk about the realms of possibility that I'm gonna be, you know, really disabled or like I could be. And how does that feel? Well, it was just heavy."*	*"but then I wouldn't know if I hadn't had it (MS), I wouldn't be who I am and I wouldn't have this perspective."* *"I've learned to be a bit kinder to myself. I'm not lazy (…) If I need to say no, you can say no."*

Lisa’s trajectory: From avoidance and maintaining control to giving in and coping with fear of disability

Time 1: Baseline	Time 2: Post-intervention	Time 3: Follow-up
“I don't even think about it, I just, it's there in the background and that's how I like to live with it really.” *“I'm a big believer in mind over matter (…) I’ll try and think through it and think not about that (pain).”*	*“this (disability) is, this is, this is what it's going to be like in, in, but then it goes out my head because I don't think about the future, I think about today.”* *“in my head I think if I stop, I'm giving into it, but I have, I have had to stop and give into it, so that's a plus really I think.”*	*“I give in to it more now than I've ever done (…) get a bit softer with it (not being able to do something) really”* *“if I think about it (physical disability), I just brush it out of my mind and I wouldn't be human if I didn't ever think about it, but I try not to dwell on it.”*

Julia's trajectory: From being judgemental about her MS to being open and self-assured with it

Time 1: Baseline	Time 2: Post-intervention	Time 3: Follow-up
"being able to accept it (wheelchair) and come to terms of it and not be too so bothered by it." *"Sometimes I just feel a bit stupid saying I've got this problem, because other people don't seem to have the day on day off situation."*	*"I'm not too worried about what other people think because I feel more reassured."* *"It was always (in the group) like if you need something you need it and it's not an issue."*	*"And maybe I feel more confident now to just say I can't."* *"I need to accept it and I think it's good in a way, because I've got it (equipment) here, but I don't have to use it. It's, but it's there if needed."*

Kate's trajectory: From resisting being dependent on others because of MS to accepting help

Time 1: Baseline	Time 2: Post-intervention	Time 3: Follow-up
"To just being disabled. Can't work, can't drive. I hate it." *"It's just annoying, my life is so dictated, 'You must do this on that day, must do that on that day"*	*"it's really annoying. 24-hour care fighting [city] Council to reduce the amount of care I get."* *"I know I've got it. I accept I've got it, but it's all the boundaries in my life because of it."*	*"Accepting that I'm disabled, wheelchair, that's it."* *"I'm more accepting of help than I was."*

Conclusions

Idiographic, longitudinal designs may address the issues presented in between-group mean-comparisons studies

More tailored psychological interventions using the Process-Based Therapy model

Include self-concept in intervention evaluation studies

Thank you!

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