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BMJ Open 'I can do this': a qualitative exploration of acceptability and experiences of a physical activity behaviour change intervention in people with multiple sclerosis in the UK

Jennifer Fortune , 1,2 Meriel Norris, Andrea Stennett, Cherry Kilbride, Grace Lavelle,² Wendy Hendrie,³ Lorraine de Souza,² Mohamed Abdul,⁴ Debbie Brewin,⁵ Lee David,⁵ Nana Anokye,⁶ Christina Victor,² Jennifer M Ryan^{2,7}

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For numbered affiliations see end of article.

Correspondence to

Dr Jennifer Fortune: fortunej@tcd.ie

ABSTRACT

Objectives The purpose of this study was to explore the experiences of people with multiple sclerosis (MS) who participated in iStep-MS, a feasibility randomised controlled trial of a behaviour change intervention that aimed to increase physical activity and reduce sedentary behaviour.

Design A qualitative approach was undertaken embedded in the feasibility randomised controlled trial. One-to-one semi-structured interviews were conducted and analysed using Framework analysis.

Setting Participants were recruited from a single MS therapy centre in the southeast of England, UK. **Participants** Sixty people with MS were randomly allocated in a 1:1 ratio to the intervention or usual care. Following a purposive sampling strategy, 15 participants from the intervention arm undertook 1:1 semi-structured interviews.

Interventions The iStep-MS intervention consisted of four therapist-led sessions over 12 weeks, supported by a handbook and pedometer.

Results Three themes were identified from the data. "I can do this": developing competence in physical activity highlights the enhanced physical activity confidence gained through goal setting and accomplishment. "I felt valued": the nurturing culture provides an overview of the supportive and non-judgemental environment created by the programme structure and therapeutic relationship. Finally, "What can I do?": empowered enactment describes the transition from the supported iStep-MS intervention to intrinsically motivated physical activity enactment.

Conclusions Overall, this study supports the acceptability of the iStep-MS intervention and identified key areas that supported participants to be physically active.

Trial registration number ISRCTN15343862.

INTRODUCTION

Multiple sclerosis (MS) is a complex progressive neurological condition that can affect the motor, sensory and nervous systems. Physical activity (PA) participation is desirable in the

Strengths and limitations of this study

- A purposive sampling frame was used to capture a range of experiences.
- Rigour and trustworthiness were enhanced by negative case analysis, peer-debriefing and maintenance of a reflexive diary.
- Participants were recruited from a single therapy centre in the southeast of England and were homogenous in ethnic background, which may limit the generalisability of the findings.

management of MS and is associated with improved symptom management and quality of life.²⁻⁴ Despite numerous reported benefits, research demonstrates that in comparison to the general population people with MS report reduced levels of PA⁵ 6 and spend more time in sedentary behaviour.⁷⁸ People with MS report difficulty in accessing support to be physically active and research suggests that this support is not routinely available.⁹ This indicates a need for new and innovative strategies to assist people with MS to change PA behaviour.

Behaviour change interventions are 'coordinated sets of activities designed to change specified behaviour patterns. 10 These interventions often involve multiple, interacting components and have demonstrated success with increasing PA and reducing sedentary behaviour in the general population. 11-13

A recent systematic review and metaanalysis which investigated the effectiveness of behaviour change interventions for increasing PA in people with MS indicated a positive effect on self-reported PA in the short term. 14 While these results are promising, wide variation in the mode and intensity of



delivery, and theoretical basis limit comparability across studies. Furthermore, there is a lack of evidence in the long-term effectiveness of such interventions and the acceptability of them for people with MS.

We developed the iStep-MS Trial, 15 a behaviour change intervention that aimed to increase PA and reduce sedentary behaviour among people with MS. Briefly, the 12-week intervention consisted of four face-to-face, individual sessions with a physiotherapist, each lasting between 30 and 45 min, an accompanying handbook and a pedometer. Intervention sessions were guided by the handbook and incorporated a range of behaviour change techniques to facilitate engagement in PA and reduction in sedentary behaviours. Techniques were drawn from the taxonomy of behaviour change techniques ¹⁶ and techniques used in each session are outlined in the online supplementary material. Brief cognitive-behavioural strategies, which aimed to address coping with negative emotions in relation to adjusting to MS and perceived stress were included in both the therapist training and participant handbooks, based on materials used in the Supportive Adjustment for Multiple Sclerosis programme. ¹⁷ Self-reflection exercises and activity monitoring diaries for tracking PA, step-count and sedentary behaviour goals were included in the handbook. The intervention was delivered by a team of four physiotherapists. Therapists had an average of 15 (2.6) years of general experience and 7 (1.4) years' experience working with people with MS.

Eligibility criteria for the iStep-MS trial were a self-reported diagnosis of MS, ability to independently walk within the home with or without a walking aid, relapse free for the past 3 months and free of unstable medical conditions (eg, unstable angina). Sixty people with MS were recruited from a single MS Therapy Centre in the southeast of England and the MS Society UK website, of whom 30 were randomised to receive the intervention. ¹⁵

To ensure successful implementation and maintenance of behaviour change, interventions must consider and match the preferences and values of people with MS. Although existing literature has explored exercise and PA experiences of people with MS, ¹⁸ ¹⁹ to date few studies have investigated the experiences, opinions and preferences of people with MS regarding behaviour change interventions. ²⁰ ²¹ Detailed qualitative exploration and analysis of the experiences of people with MS in such programmes has important implications for intervention refinement and informing future implementation strategies to enhance PA. This study aimed to explore the user experience of the iStep-MS trial.

METHODS

The feasibility, acceptability and safety of the iStep-MS intervention were evaluated by conducting a feasibility randomised controlled trial accompanied by a parallel embedded mixed methods process evaluation. Using a qualitative research approach, the present study explored

the participant's experience of the intervention arm of the feasibility randomised controlled trial.

To elucidate the participant experience, one-to-one semi-structured interviews were conducted with a purposeful sample of 15 people following completion of the 12-week intervention. The sample in the present study was determined by what some authors have described as symbolic representation, that is, based on features that the literature suggests are relevant to engagement with PA and experiences of living with MS more generally which we believed to be of relevance to the study.²² A sampling frame involved key criteria including gender: to ensure representation reflective of the larger MS population and acknowledging that gender may impact activity choice and engagement, ²³ age (older or younger than 60 years) to capture participants with different life commitments (eg, employment), which has been shown to impact on engagement with PA24 and low and high PA engagement (above or below 5000 steps per day) to capture the experiences of those already active and those less so in order to consider the impact that previous engagement may have.²⁵ All participants who were approached agreed and provided written informed consent prior to participation in the interview.

To reduce any potential influence on the participant's response interviews were conducted by an experienced qualitative researcher (MN) who was not involved in intervention provision. Interviews were conducted at a location and time of the participants' choosing; including their own homes or a private room at the MS Centre. Interviews were conducted on average 31 (11.9) days following completion of the intervention.

The topic guide was developed in consultation with the wider research team. It was designed to explore the participants' experiences of the intervention while taking the aims of the process evaluation into account. As a consequence, it has a number of specific questions relating to trial feasibility, acceptability and safety. This paper focuses on the user experience of the intervention. Interviews began with broad questions on the individual's history of MS and discussion of past and current engagement with PA. This was followed by a more focused exploration of participation in the intervention. Open-ended questions, with neutral prompts as required, were used with sufficient flexibility to pursue issues introduced by the participants. Indicative content of the topic guide is shown in table 1. Interviews lasted from 51.6 to 88.6 min each (mean 66.9 min).

Audio-recorded interviews were transcribed verbatim, anonymised and imported into the qualitative data management software (NVivo V.12: QSR International). All participants' names were replaced with pseudonyms, and identifiable information was removed.

Data were analysed using Framework analysis.²⁶ Framework analysis is a transparent and iterative process of analysing qualitative data. It allows the researcher to incorporate both deductive and inductive codes which was appropriate for this study where specific questions in



Table 1 Indicative interview topic guide content	
Background	 History of MS. The physical, psychological and social impact of MS.
Experiences in iStep-MS trial	 Drivers for participation. Likes and dislikes of the programme. Expectation vs reality. Changes as a result of the programme.
Taking part in the research	 Impact/effect of group allocation. Experience of being monitored. Experience of monitoring tools and questionnaires. Interaction with the research team/assessors.

MS, multiple sclerosis.

relation to feasibility and acceptability were identified a priori, but experiential aspects were not. It involved five iterative stages of analysis: familiarisation, identifying thematic framework, labelling, charting and mapping and interpretation.

During familiarisation with data, the transcripts were read several times and both initial deductive and inductive codes were identified. Deductive codes originated from questions related to the process evaluation (ie, feasibility, acceptability) including communication with the research team, the experience of randomisation and trial information. The results presented here focus on the user experience of the iStep-MS intervention which were all inductive in development. The rigour of this stage was supported by independent dual analysis and coding of the first three transcripts by two researchers (JF, MN) following which the codes were discussed and agreement reached. Identifying the thematic framework involved different levels of abstracting of codes to develop key ideas used for subsequent phases. The conceptual framework was developed and discussed with the co-researcher prior to the next phase of analysis. During the labelling phase, the thematic conceptual framework was applied to the entire data set to ensure total coverage and further developed through the iterative process if new areas were identified. Charting is a process for summarising and synthesising the data to facilitate identification of thematic links and was conducted using a thematic matrix. The final phase is mapping and interpretation in which the final categories and their relationships and interactions are described. This process was facilitated through diagrammatical representations of the themes and critical discussion with the research team (MN, JR, AS and CK) to ensure themes were comprehensive and enhance the depth of analysis. Disagreements were resolved through peer debriefing until clarity and consensus were obtained. Preliminary results and interpretations were shown to the advisory group including people with MS and therapists who were given the opportunity to reflect on the findings. No changes were made as a consequence of this process. The phases are iterative resulting in continuous movement between the transcripts, codes and thematic charts. This method also provides a clear audit trail, which enables transparency. Acknowledging the primary researcher's (JF) background in physiotherapy and role in the development team several strategies were put in place to ensure the trustworthiness of the analytical process including the maintenance of a reflexive diary and consideration of negative case analysis to identify elements of the data that did not support or appeared contradictory to identified patterns.

Patient and public involvement

An advisory group composed of two people with MS and four clinicians with a special interest in neurology co-developed the intervention. The advisory group convened five times over the trial. Four meetings were held during the development phase and a further dissemination meeting was held following intervention completion.

Members of the advisory group who have MS were involved in reviewing and critiquing trial documentation including the trial protocol, participant information leaflets, consent forms, invite letters, recruitment material and questionnaires. They contributed to the development of the intervention by iteratively reviewing and providing content and design feedback on successive versions of the handbook. One member of the group who has MS assisted with piloting the intervention and recorded a training video for the intervention therapists. Preliminary results from the interviews were shared with them and comments invited regarding the interpretations presented. At the final dissemination meeting, they advised on the most relevant format and place of publication in order to maximise the impact of the findings for people with MS.

RESULTS

A summary of participant demographic and clinical characteristics is shown in table 2. Participants were 66% female, with an age range of 39–71 years; time since diagnosis ranged from 4 to 42 years. The disease course was relapsing-remitting (n=7), primary progressive (n=3) and secondary progressive (n=5). Nine participants had an



Table 2 Participant demographic and clinical data

ID	Age range (years)	Sex	Clinical course	Time since diagnosis (years)	Physical activity engagement (above or below 5000 steps)	Functional walking level	Ethnicity
Harry	46–50	Male	SPMS	12	<5000 steps)	Independent with aid	White
Julia	61–65	Female	PPMS	7	<5000	Independent	White
Anna	56–60	Female	SPMS	27	<5000	Independent with aid	White
William	71–75	Male	SPMS	23	<5000	Independent with aid	White
Rose	61–65	Female	SPMS	21	<5000	Independent with aid	White
Adam	51–55	Male	PPMS	5	<5000	Independent with aid	White
Ella	51–55	Female	RRMS	10	>5000	independent	White
Hannah	41–45	Female	RRMS	4	>5000	Independent	White
Maisie	51–55	Female	RRMS	20	>5000	Independent	White
Joe	66–70	Male	RRMS	42	<5000	Independent with aid	White
Sophie	51–55	Female	RRMS	12	>5000	Independent	White
Emma	36–40	Female	RRMS	5	>5000	Independent	White
Olivia	61–65	Female	SPMS	12	<5000	Independent with aid	White
Emily	61–65	Female	RRMS	8	>5000	Independent with aid	White
Mark	61–65	Male	PPMS	8	<5000	Independent with aid	White

PPMS, primary progressive multiple sclerosis; RRMS, relapsing-remitting multiple sclerosis; SPMS, secondary progressive multiple sclerosis.

average daily step count of fewer than 5000 steps. The desired sample was achieved demonstrating a range in all variables of interest. There was a mix of employment and habitation statuses however, it is worth noting that all participants were white.

Summary of themes

Three themes were identified following analysis. "I can do this": developing competence in physical activity describes the increase in confidence to initiate behaviour and explore personal exercise boundaries through goal attainment. "I felt valued": the nurturing culture refers to the supportive environment within which the iStep-MS programme was conducted. "What can I do?": empowered enactment explores the participant's contemplation of the transition from supported behaviour change within the trial structure to autonomous self-management.

Theme 1: "I can do this": developing competence in physical activity

As participants reflected on their progression through the intervention, they expressed an increase in their perceived confidence to undertake PA. This change resulted in a growing sense of competence in their own ability to be

active. Three distinct features of the programme: pushing boundaries, stepwise incremental development and individualisation were deemed to facilitate this competence shift and are described next.

Active exploration of personal boundaries permitted participants in the iStep-MS programme to safely test and challenge their perceived PA capability. Successful attainment of predefined goals which pushed the boundaries of their physical capability and capacity recalibrated participants' views of their ability and led to a renewed trust of bodily signals and confidence in achieving PA targets.

I discovered that round this block is ten minutes. And it was hard work to go...getting round there once at a vaguely fast pace (which) was slightly scary. I didn't do it on my own because I was worried about tripping and then I was worried about getting stuck and not being able to finish it. But now I'd quite happily—go round the block, I can do two or three times one after another, quite fast, on my own and I'm not worried anymore. It's built a lot of confidence in me... (Sophie)



For Sophie and others on the programme, boundary exploration was successfully achieved by breaking large goals down into smaller steps. Cumulative achievement of microgoals was important for several reasons. It made perceived insurmountable targets seem achievable. Personal benchmarks of capability were redefined with completion of each step of the goal trajectory which led to capability recognition. Tackling performance outcomes incrementally allowed participants to work within their ability zone. Achieving each step safely without injury or relapse diminished apprehension and provided encouragement to push the boundaries further. Finally, staggered goal achievement dispelled the idea that changing behaviour must involve significant lifestyle modifications.

While these small steps may have seemed insignificant from an objective perspective, the beneficial effect on competency and mastery to the individual was evident as demonstrated in the following extended quote.

One of the things that I put down as my target was to walk into town. Now, that sounds oh, just walk into town. Now, I know I can walk because I put one foot in front of the other.... the one thing that MS does, physically, it knocks your confidence for six because you're not as independent, I didn't want to go out on my own.

Then I decided, and I did it in small steps, I walked there, walked back, walked there, walked back, had a few where I didn't walk as far as, or I got, and I thought no, I can't do this, I can't do this. The day I walked into town, on my own, without anybody there, was absolutely liberating. I can do this. I can do this, and from then, from that moment onwards, it was, you know, I can do this, I can do anything I want to do... (Emily)

As Emily indicates, incremental goal stages were invaluable, but full independent goal completion provided external confirmation of physical ability and was a crucial milestone in the enhancement of exercise confidence.

An important feature of the goals was that they were personally meaningful, linked with values and tailored to the individuals' specific circumstances.

I think they mean more. If it's something that you've decided is important to you, rather than somebody deciding for you. I mean, one question on page whatever, and it said, 'What's important to you in your life—is it your friends, relatives and everything?' And I thought about that and I thought, 'No, the things that are really important to me is my independence'. And it all came out of that. (Joe)

Joe's description above illustrates how underpinning the goal setting with personal reflection driven by the participant facilitated his sense of autonomy and control over the activities. Other participants described similar experiences reflecting on how this reversed the power dynamic experienced in previous medical interactions. Taking ownership of individually tailored goals ensured investment in the programme and facilitated maintenance of activity goals.

Individual tailoring was possible due to the competence of the therapy team to distil personally meaningful themes through their in-session conversations.

my children are what I want to be able to do and do things with them. So from discussions with (the therapist), she picked up that it was important to me that I was able to do those sort of things. So then it became things—suggestions from here (Emma)

The importance of goal relevance was also emphasised when it was missing. Adam, for example, preferred cycling to walking, but due to a perceived required emphasis on step count, this was prioritised creating a mismatch between his goals and desired activities as illustrated by the following quote:

....what I felt was a bit of a pain was when I had to feel I was doing a walk to the shop because I needed to increase my step count...if I need to get a paper or something then I'll prefer to take the bike, it's quicker, it's less hassle, I'm straight out and walking to the shop is a bit boring, the terrain's a bit awkward. (Adam)

While the achievement of predefined goals promoted feelings of competence and was a strong recurring theme, failure to reach PA targets led to feelings of disappointment and decreased motivation emphasising the importance of tailoring goals to individual capability.

Probably the one thing that I do do a lot, which is get disheartened when I don't achieve the type of goals that I want to achieve (Hannah)

Theme 2: "I felt valued": the nurturing culture

Competence development was also enhanced and facilitated by the nurturing culture embodied in the iStep-MS programme. This supportive environment was created through the intervention structure such as the face-to-face sessions with a consistent therapist and importantly through the actions, approach and expertise of the treating therapists who made participants feel valued.

Face-to-face interaction across four intervention sessions facilitated the development of a personal and supportive relationship between the therapist and participant. Through the conversational format, participants could articulate their thoughts and feelings regarding topics of importance. Subsequently, participants felt understood and were more forthcoming as a result of the rapport developed. In contrast to previous clinical experiences which often felt rushed, therapist contact across the intervention sessions fostered a sense of relatedness by making participants feel listened to and valued. This was crucial in improving confidence and self-efficacy to engage in PA goals.



I think I felt listened to, I think I felt valued. With the NHS nurses just popping in and out, you just feel like they've got a job to do and then they go on. With this little chat, she felt like she was spending time with me and I think it's about how personalised it then became. It was much more personal. (Hannah)

Reliable and consistent contact enhanced psychosocial well-being and provided reassurance to allay fears or uncertainties. Key to the development of this relationship was a sense of partnership. In contrast to prior clinical dialogues which followed a paternalistic approach, during the iStep-MS sessions the participant was valued as the expert who led the agenda of the session which encouraged agency and autonomy.

Well if it's come from me, it's what I want to do. It's the way I want to achieve it, not the way they want, it's what I want to do. That's important isn't it? (Rose)

A balance between therapist direction and participant centredness was embodied through collaborative goal setting which encouraged power-sharing: a 'shoulder-toshoulder' approach. Equity and a sense of responsibility because of that partnership was also evident.

Well, people do put in the effort here (MS centre) and I think it's, there's an element of fairness in actually doing your own bit, rather than me just rolling up here every three or 4weeks for a chat with (physiotherapist). (Mark)

While partnership was both facilitatory and valued, participants also appreciated that the therapists' role nurtured accountability. Between-session monitoring motivated participants to instigate positive health changes as their efforts would be discussed in the next session. Accountability was often driven by therapist delivered affirmation which provided supportive reassurance to enable participants to engage with activity.

No I think seeing the physiotherapist; she kept you going, kept you monitored for the next step. I think it's important on a regular basis to achieve your target and then talk about your disappointments or your achievements, to be honest. (William)

As the intervention progressed participants gave examples of more internal accountability. Activities were completed often against the odds "just because we (husband and herself) decided to set some targets", as Maisie explained.

While this sense of accountability was valued by many, Emma expressed a clear desire for personal rather than external accountability

But I don't think having it written down that I was going to go for a walk every week for half an hour was right for me. I didn't want—I think it comes down to accountability again, I didn't want it to make me accountable. I wanted to be accountable myself. (Emma)

This view is important to emphasise as it highlights the need for the programme to have enough flexibility to accommodate such preferences.

An important aspect of the interaction that made accountability more acceptable was the non-judgemental spirit conveyed by the therapist during the intervention sessions. Affirmative interactions which embodied empathy were valuable when goals were not achieved in this diligent population creating an environment that was inherently unpressurised.

on the last session when I went to see (the physiotherapist) and I thought oh, I haven't filled in all my things and I almost felt like a schoolchild again... she was lovely about it...she said, 'Well, I know you've given it some thought because you've written some things down and it's just great that because we can talk about it', and it was phew, a big relief. (Ella)

Participants described how this facilitated a safe environment where they felt at ease in communicating their struggles and critically challenging their personal barriers to PA

Theme 3: "What can I do?": empowered enactment

Participation in the trial facilitated experiences of mastery through an exploration of ability and successful goal completion within an autonomy-supportive environment. These factors enhanced participant control with a corresponding positive effect on confidence. As indicated by Maisie above, the result was evidence of participants managing their own behaviour which allowed them to be autonomous in goal completion independent of the infrastructure provided by the iStep-MS intervention.

A key message which resonated with participants was the value of embedding small changes in everyday life. Over time, they found themselves independently looking for more opportunities to achieve this.

I think I was probably quite pleased that I get up and fill the dishwasher more than I used to do probably so all those light things which means you're not just sat on the sofa at the end of a meal watching TV, you're thinking, well, what can I do, what is there to do, there's always something and just having that kind of, right, I'll get and do something else. (Adam)

Similarly, pacing was used as a self-management skill and planned breaks were re-framed and perceived to be an active response to symptom management rather than a passive coping approach to exhaustive activity. Integration of planned breaks allowed participants to allocate finite energy stores to prioritised activity and to take back control by ensuring PA was suspended before exhaustion arose. This shift in attitude caused participants not to view their day in blocks of opportunity to rest but rather look for any opportunity to complete activity however small.

Whereas before I would go and do jobs and I would just go into them and say, 'OK I've got to sit down



now...' Whereas now because I have paced myself I have got a bit more energy. OK the job has taken longer but I am all right, at the end of it I am all right. I have paced myself and I don't need half an hour sitting down. (Harry)

Exercise planning was another technique that participants identified as a continuing skill. It negated competing commitments, ensuring PA became part of a routine and facilitated coping planning which created contingency plans to circumvent or compensate periods of unavoidable sedentary behaviour or planned lapses like holidays that might have otherwise jeopardised progress.

... I'm going to spend hours on a train next week going to Cardiff, but I'm going to walk from the train station to the office and not get a taxi, and that's going to be, you know, the best part of a mile each way, and those are the sort of things, how do I work around? yes, I have got to sit in a car for so long, I'm going to be on a train for so long, what am I going to do? How am I going to put some physical activity into it? (Maisie)

Participation in the intervention ultimately empowered participants with the knowledge, skills and resources to exert positive control and choice over their behaviours. Participants felt competent to enact their desired lifestyle changes independently and ongoing sustained engagement in PA behaviours was anticipated by many participants.

...well it's just I keep saying to my wife and keep reminding myself what I used to do in the past and perhaps how much more, a little bit more I could do in the future. One mustn't stop now and say that is it. (William)

DISCUSSION

The principal objective of this study was to explore participants' views and experiences of the iStep-MS intervention. Participants in the iStep-MS trial found the programme acceptable and reported a range of perceived benefits and personally meaningful changes to activity. Behaviour change techniques and the support embodied by the non-judgemental partnership formed between therapist and client facilitated confidence to engage in PA and equipped participants with the skills for ongoing behaviour change.

Competence in PA was facilitated through personally meaningful goal achievement, supported by reflection and self-monitoring. Goal setting is a widely used strategy to support self-management and facilitate behaviour change, ^{27–30} which has positive associations with PA for people with MS. ³¹ In line with previous research, the value of a 'small changes' approach to lifestyle modification was emphasised in the present study. ³² Successful goal attainment through this approach, combined with immediate

validation of effort through self-monitoring^{33 34} promoted feelings of competence and was integral for increasing confidence and self-efficacy.³⁵ Self-efficacy is a dominant contributor to PA participation among people with MS³⁶ and the feelings of empowerment demonstrated in the present study support the role of goal-setting in building confidence. Imbued with an enhanced sense of mastery, participants began to take ownership of their PA behaviour by flexibly modifying their own goals between sessions with the physiotherapist at any time, at their own discretion.³⁷ In line with previous research, ³⁸ adaptive goal adjustment that was self-initiated under personal volition promoted feelings of psychological well-being and ultimately promoted autonomy in goal achievement.^{39 40}

Autonomy was further developed through the support of a strong therapeutic relationship. Understanding the participants' personal context allowed the creation of an intervention that was individualised to participants' needs and values. PA engagement is influenced by a myriad of factors for people with MS^{18 41} and its heterogeneous presentation requires individualisation of the format of PA interventions⁴² highlighting the importance of context-appropriate goals that respond to personal need.⁴³

Alignment of goals with personal preferences in the present study increased feelings of ownership and subsequently enhanced perceptions of control over behaviour change implementation. Treating the individual as the expert in their situation aligns with the principles of patient-centred care and expert physiotherapeutic practice. ⁴⁴ Additionally, shared decision making in goal setting has been found to enhance participant satisfaction ⁴⁵ and behaviour changes outcomes. ⁴⁶ This may be particularly important for people with MS who are significantly more likely to favour shared decision making with healthcare professionals compared with other chronic conditions. ⁴⁵

Crucial to this sense of individualisation was the therapeutic partnership developed across four intervention sessions, which lasted between 30 and 45 min. Of participants interviewed, six reported a prior relationship with their intervention therapist through their involvement with the MS therapy centre, which may have hastened the establishment of the therapeutic relationship. However, regardless of prior relationship, time spent interacting with their therapist was emphasised as a key factor in participant engagement and perceived acceptability of the programme. Behaviour change interventions have been delivered to people with MS through diverse modes including group sessions⁴⁷ 48 and technology-mediated approaches, for example, telephone, 49-51 and internetbased counselling.⁵² Although such modes of delivery may require less resources than a face-to-face intervention, our findings suggest that the formation of a nonjudgemental partnership was key to the perceived impact of the programme. Presently, there is a dearth of information examining preferred intervention delivery mode in people with MS, however, research in the general population⁵³ and other chronic conditions⁵⁴ 55 generally



supports a preference for face-to-face interventions. Given the importance of the therapeutic relationship in facilitating behaviour change, further evaluation of the cost-effectiveness of a face-to-face intervention, relative to a telephone or internet intervention, is warranted.

The programme appeared to provide participants with the skills and resources for continued PA engagement after clinician contact ceased. Such potential for continuation is essential given the short-term nature of the programme and evidence that prolonged commitment to change is often not sustained.¹⁴ Intrinsic motivation has been shown to predict PA⁵⁶ and appeared to be a driving force behind PA intention and behaviours as participants progressed through the programme. Commitment to change was evidenced by engagement with and embedding of self-regulatory strategies into daily life including pacing, exercise scheduling and coping planning. These techniques have demonstrated efficacy in promoting behaviour change⁵⁷ and allowed participants in the present study to anticipate future problems and select alternative solutions ensuring intention for behaviour change maintenance.

Limitations

The iStep-MS trial was conducted in a single, non-National Health Service centre in the southeast of England, which may influence the generalisability of findings. Six participants who were interviewed had a prior relationship with the therapist who implemented their intervention through their involvement in the MS therapy centre. It is possible that this prior rapport may have influenced their experience of the intervention. Furthermore, there was a lack of ethnic diversity and a limited age span within the participant group. While participants reported positive experiences and perceived impact of the iStep-MS trial, these reports need to be considered alongside the safety, fidelity and indicative efficacy results when considering whether iStep-MS warrants further development.

Strengths of this study include the use of a clear audit trail and a variety of strategies that aimed to enhance transparency and rigour. Although the interviews represent a subsample of participants, a comprehensive sampling approach was used to ensure representation of viewpoints from a range of participants.

CONCLUSION

Support to be physically active is not as readily available or accessible as required for people with MS. The present findings demonstrate that a therapist supported behaviour change intervention is acceptable to people with MS and resulted in perceived changes to activity behaviour.

Key features that enhanced acceptability included goal achievement within a therapist supported nonjudgemental collaborative approach. Results provide evidence of the value of a therapeutic relationship in facilitating behaviour change. Intervention implementation may be improved if PA preferences can be elucidated and implemented among individuals with MS. It is possible that these key features, which draw on evidence, have the potential to result in long-term engagement in PA and enhanced health outcomes for people with MS.

Author affiliations

¹University of Dublin Trinity College, Dublin, Ireland

²Ageing Studies Theme, Institute of Environment, Health and Societies, Brunel University London, Uxbridge, UK

³MS Therapy Centre, Norwich, UK

⁴The Berkshire MS Therapy Centre, Reading, UK

⁵10 Minute CBT, London, UK

⁶Health Economics Research Group, Brunel University London, Uxbridge, UK

⁷Department of Public Health and Epidemiology, RCSI, Dublin, Ireland

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ORCID ID

Jennifer Fortune http://orcid.org/0000-0001-8971-1236

REFERENCES

- Frohman EM, Racke MK, Raine CS. Multiple sclerosis the plaque and its pathogenesis. N Engl J Med Overseas Ed 2006;354:942–55.
- Carter A, Daley A, Humphreys L, et al. Pragmatic intervention for increasing self-directed exercise behaviour and improving important health outcomes in people with multiple sclerosis: a randomised controlled trial. Multiple Sclerosis Journal 2014;20:1112–22.
- Grover SA, Aubert-Broche B, Fetco D, et al. Lower physical activity is associated with higher disease burden in pediatric multiple sclerosis. Neurology 2015;85:1663–9.
- Tallner A, Waschbisch A, Hentschke C, et al. Mental health in multiple sclerosis patients without limitation of physical function: the role of physical activity. Int J Mol Sci 2015;16:14901–11.
- Motl RW, Sandroff BM, Kwakkel G, et al. Exercise in patients with multiple sclerosis. Lancet Neurol 2017;16:848–56.
- Motl RW, McAuley E, Snook EM. Physical activity and multiple sclerosis: a meta-analysis. *Mult Scler* 2005;11:459–63.
- Veldhuijzen van Zanten JJ, Pilutti LA, Duda JL, et al. Sedentary behaviour in people with multiple sclerosis: is it time to stand up against MS? Mult Scler 2016;22:1250–6.
- Sasaki JE, Motl RW, Cutter G, et al. National estimates of selfreported sitting time in adults with multiple sclerosis. Mult Scler J Exp Transl Clin 2018;4.



- (NICE) NIfHaCE. NICE quality standard [QS108], 2016. Available: http://www.nice.org.uk/guidance/qs108 [Accessed 20 Dec 2018].
- Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implementation Science* 2011;6.
- Darker CD, French DP, Eves FF, et al. An intervention to promote walking amongst the general population based on an 'extended' theory of planned behaviour: A waiting list randomised controlled trial. Psychol Health 2010;25:71–88.
- Ashford S, Edmunds J, French DP. What is the best way to change self-efficacy to promote lifestyle and recreational physical activity? A systematic review with meta-analysis. *Br J Health Psychol* 2010:15:265–88.
- Williams SL, French DP. What are the most effective intervention techniques for changing physical activity self-efficacy and physical activity behaviour--and are they the same? *Health Educ Res* 2011;26:308–22.
- Sangelaji B, Smith CM, Paul L, et al. The effectiveness of behaviour change interventions to increase physical activity participation in people with multiple sclerosis: a systematic review and metaanalysis. Clin Rehabil 2016;30:559–76.
- Ryan JM, Fortune J, Stennett A, et al. Changing physical activity behaviour for people with multiple sclerosis: protocol of a randomised controlled feasibility trial (iStep-MS). BMJ Open 2017;7:e018875.
- Michie S, Ashford S, Sniehotta FF, et al. A refined taxonomy of behaviour change techniques to help people change their physical activity and healthy eating behaviours: the CALO-RE taxonomy. Psychol Health 2011;26:1479–98.
- Moss-Morris R, Dennison L, Landau S, et al. A randomized controlled trial of cognitive behavioral therapy (CBT) for adjusting to multiple sclerosis (the saMS trial): does CBT work and for whom does it work? J Consult Clin Psychol 2013;81:251–62.
- work? *J Consult Clin Psychol* 2013;81:251–62.
 18. Stennett A, De Souza L, Norris M. The meaning of exercise and physical activity in community dwelling people with multiple sclerosis. *Disabil Rehabil* 2018;100:1–7.
- Dlugonski D, Joyce RJ, Motl RW. Meanings, motivations, and strategies for engaging in physical activity among women with multiple sclerosis. *Disabil Rehabil* 2012;34:2148–57.
- Crank H, Carter A, Humphreys L, et al. Qualitative investigation of exercise perceptions and experiences in people with multiple sclerosis before, during, and after participation in a personally tailored exercise program. Arch Phys Med Rehabil 2017;98:2520–5.
- Barnard E, Brown CR, Weiland TJ, et al. Understanding barriers, enablers, and long-term adherence to a health behavior intervention in people with multiple sclerosis. *Disabil Rehabil* 2018;9:1–11.
- 22. Ritchie JLJ, Elam G, Tennant R, et al. Qualitative research practice: a guide for social science students and researchers. 2nd edn. London: Sage. 2014: 111–42.
- Anens E, Emtner M, Zetterberg L, et al. Physical activity in subjects with multiple sclerosis with focus on gender differences: a survey. BMC Neurol 2014;14:47.
- Streber R, Peters S, Pfeifer K. Systematic review of correlates and determinants of physical activity in persons with multiple sclerosis. *Arch Phys Med Rehabil* 2016;97:633–45.
- Smith CM, Hale LA, Mulligan HF, et al. Participant perceptions of a novel physiotherapy approach ("Blue Prescription") for increasing levels of physical activity in people with multiple sclerosis: a qualitative study following intervention. *Disabil Rehabil* 2013;35:1174–81.
- Ritchie JLJ. Qualitative research practice: a guide for social science students and researchers. London: SAGE Publishers, 2009.
- Rosewilliam S, Roskell CA, Pandyan AD. A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation. *Clin Rehabil* 2011;25:501–14.
- Scobbie L, Dixon D, Wyke S. Goal setting and action planning in the rehabilitation setting: development of a theoretically informed practice framework. Clin Rehabil 2011;25:468–82.
- Siegert RJ, McPherson KM, Taylor WJ. Toward a cognitive-affective model of goal-setting in rehabilitation: is self-regulation theory a key step? *Disabil Rehabil* 2004;26:1175–83.
- McCorkle R, Ercolano E, Lazenby M, et al. Self-Management: enabling and empowering patients living with cancer as a chronic illness. CA Cancer J Clin 2011;61:50–62.
- Casey B, Coote S, Shirazipour C, et al. Modifiable psychosocial constructs associated with physical activity participation in people with multiple sclerosis: a systematic review and meta-analysis. Arch Phys Med Rehabil 2017;98:1453–75.

- Stuifbergen AK, Becker H, Timmerman GM, et al. The use of individualized goal setting to facilitate behavior change in women with multiple sclerosis. J Neurosci Nurs 2003;35:94–9.
- Tudor-Locke C, Lutes L. Why do pedometers work?: a reflection upon the factors related to successfully increasing physical activity. Sports Med 2009;39:981–93.
- Fukuoka Y, Lindgren T, Jong S. Qualitative exploration of the acceptability of a mobile phone and pedometer-based physical activity program in a diverse sample of sedentary women. *Public Health Nurs* 2012;29:232–40.
- Bandura A. Self-Efficacy mechanism in human agency. Am Psychol 1982;37:122–47.
- Kayes NM, McPherson KM, Taylor D, et al. Facilitators and barriers to engagement in physical activity for people with multiple sclerosis: a qualitative investigation. *Disabil Rehabil* 2011:33:625–42.
- McEwan D, Harden SM, Zumbo BD, et al. The effectiveness of multicomponent goal setting interventions for changing physical activity behaviour: a systematic review and meta-analysis. Health Psychol Rev 2016;10:67–88.
- Neter E, Litvak A, Miller A. Goal disengagement and goal reengagement among multiple sclerosis patients: relationship to wellbeing and illness representation. *Psychol Health* 2009;24:175–86.
- Bodenheimer T, Handley MA. Goal-setting for behavior change in primary care: an exploration and status report. *Patient Educ Couns* 2009:76:174–80.
- Sevick MA, Trauth JM, Ling BS, et al. Patients with complex chronic diseases: perspectives on supporting self-management. J Gen Intern Med 2007;22(S3):438–44.
- Stennett A, De Souza L, Norris M. Physical activity and exercise priorities in community dwelling people with multiple sclerosis: a Delphi study. *Disabil Rehabil* 2018;40:1686–93.
- Rietberg MB, Brooks D, Uitdehaag BMJ, et al. Exercise therapy for multiple sclerosis. Cochrane Database Syst Rev 2005;85.
- Franklin M, Lewis S, Willis K, et al. Controlled, constrained, or flexible? how self-management goals are shaped by patient-provider interactions. Qual Health Res 2018:1049732318774324.
- 44. Jensen GM, Gwyer J, Shepard KF, et al. Expert practice in physical therapy. *Physical Therapy* 2000;80:28–43.
- Hamann J, Neuner B, Kasper J, et al. Participation preferences of patients with acute and chronic conditions. Health Expect 2007;10:358–63.
- Krist AH, Tong ST, Aycock RA, et al. Engaging patients in decisionmaking and behavior change to promote prevention. Stud Health Technol Inform 2017;240:284–302.
- Ennis M, Thain J, Boggild M, et al. A randomized controlled trial of a health promotion education programme for people with multiple sclerosis. Clin Rehabil 2006;20:783–92.
- 48. Plow MA, Mathiowetz V, Lowe DA. Comparing individualized rehabilitation to a group wellness intervention for persons with multiple sclerosis. *Am J Health Promot* 2009;24:23–6.
- Bombardier CH, Cunniffe M, Wadhwani R, et al. The efficacy of telephone counseling for health promotion in people with multiple sclerosis: a randomized controlled trial. Arch Phys Med Rehabil 2008;89:1849–56.
- Bombardier CH, Ehde DM, Gibbons LE, et al. Telephone-based physical activity counseling for major depression in people with multiple sclerosis. J Consult Clin Psychol 2013;81:89–99.
- Finlayson M, Preissner K, Cho C, et al. Randomized trial of a teleconference-delivered fatigue management program for people with multiple sclerosis. Mult Scler 2011;17:1130–40.
- Dlugonski D, Motl RW, Mohr DC, et al. Internet-Delivered behavioral intervention to increase physical activity in persons with multiple sclerosis: sustainability and secondary outcomes. Psychol Health Med 2012;17:636–51.
- Short CE, Vandelanotte C, Duncan MJ. Individual characteristics associated with physical activity intervention delivery mode preferences among adults. Int J Behav Nutr Phys Act 2014;11.
- Forbes CC, Plotnikoff RC, Courneya KS, et al. Physical activity preferences and type 2 diabetes: exploring demographic, cognitive, and behavioral differences. *Diabetes Educ* 2010;36:801–15.
- Jones LW, Courneya KS. Exercise counseling and programming preferences of cancer survivors. Cancer Pract 2002;10:208–15.
- Keatley D, Clarke DD, Hagger MS. Investigating the predictive validity of implicit and explicit measures of motivation on condom use, physical activity and healthy eating. *Psychol Health* 2012;27:550–69.
 Sniehotta FF, Scholz U, Schwarzer R. Action plans and coping plans
- Sniehotta FF, Scholz U, Schwarzer R. Action plans and coping plans for physical exercise: a longitudinal intervention study in cardiac rehabilitation. *Br J Health Psychol* 2006;11:23–37.