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“Activity Matters was great - I now realize: if I move, I'm fitter.”: development and process evaluation of a web-based program for persons with multiple sclerosis

Dissertation

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RESEARCH ARTICLE



“Activity Matters was great - I now realize: if I move, I’m fitter.”: development and process evaluation of a web-based program for persons with multiple sclerosis

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ABSTRACT

Purpose: Research shows that persons with mild to moderate multiple sclerosis are less physically active than healthy controls even though they would benefit from it. This study focusses on the feasibility testing and process evaluation of the pilot study of *Activity Matters*, a twelve-week web-based program, from Ireland, to increase physical activity in this population.

Materials and Methods: The intervention was adapted to local circumstances in Hamburg, Germany and consists of eleven modules incorporating behavior change techniques. After feasibility had been confirmed, 43 persons with multiple sclerosis participated in a pilot study with a pre-post, single-group intervention design. Qualitative data was collected with questionnaires and semi structured interviews. Physical activity level and stage of change was measured quantitatively.

Results: Participants had a mean age of 49.5 years (*SD* 9.29) and an average Patient Determined Disease Step Score of 2.2 (*SD* 1.47). Thirty-six participants answered the follow-up questionnaire. On average 9.8 modules were processed within 13 weeks. Each tool for behavior change was perceived as helpful except the chat group. Physical activity levels increased significantly from pre- to post intervention (*p*-value 0.042, *Cohen’s d*=0.35).

Conclusions: The results indicate that *Activity Matters* is feasible and satisfactory and may change activity levels.

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KEYWORDS

Multiple sclerosis; physical activity; eHealth program; feasibility testing; pilot study

► IMPLICATIONS FOR REHABILITATION

- *Activity Matters* provides a twelve-week web-based self-management program to increase PA which is feasible and well accepted by middle aged, mild to moderately impaired persons with MS.
- Persons with MS in this online program were pleased with the overall content and the self-regulation strategies, however some were seeking for more personal contact and interaction with the study team and other participants.
- Stronger individualisation of web-based programs to the diverse needs of participants remains a challenge that has to be solved in the future.

Abbreviations: MS: Multiple Sclerosis; PA: Physical Activity; MRC: Medical Research Council; BCW: Behavior Change Wheel; DMSG: German MS Society; UMC: University Medical Center; PDDS: Patient Determined Disease Steps Score; *GLTEQ*: Godin Leisure Time Exercise Questionnaire; *R*: Range; *Mdn*: Median; *RRMS*: Relapsing-Remitting Multiple Sclerosis; *PPMS*: Primary Progressive Multiple Sclerosis; *SPMS*: Secondary Progressive Multiple Sclerosis

Introduction

Multiple sclerosis (MS) is a chronic inflammatory autoimmune disease associated with demyelination in the central nervous system. With a prevalence of about 240.000 people in Germany [1], MS represents one of the main reasons for neurological disability in young adults [2, 3]. Persons with MS have been discouraged from exercising for many years to prevent thermosensitive changes in the conduction of neurostimuli resulting in weakness, disbalance and paresthesia called the *Uthoff phenomenon* [4]. However, there is consensus nowadays that physical activity (PA) and exercise, in particular, make a major contribution to improving fitness, mobility and quality of life, but also MS-specific symptoms

such as fatigue and depression [5, 6]. Based on *Latimer-Cheung’s* evidence-based minimal recommendations for PA among persons with MS published in 2013 [7], recommendations were recently revised and, respecting comorbidities and impairment, aligned to those for healthy people. Thus, it is suggested, for healthy people as well as persons with MS, to be active for a minimum of 150 min per week either through exercising or daily activities [6]. Nevertheless, research shows that many persons with MS are less physically active than healthy controls [8] and would benefit from increasing their level of PA [9, 10]. *Dalgas* points out that persons with MS are often left with misleading terminology and a lack of definitions for sports [11], e.g., by using the terms “exercise”

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and "PA" interchangeably. As recently discussed by *Riemann-Lorenz* [12, 13], environmental barriers might prevent persons with MS from being physically active on a regular basis: persons with MS, specifically those with advanced disability, seem to have an unmet need for available, high quality and variable sports programs. For those people, the opportunity to exercise at home seems to be important for remaining physically active in the long term [12]. Survey study results among persons with MS [13] demonstrate that inactive people have greater deficits in the intention and capability of behavioral regulation (e.g., action planning and action control) than long-term physically active people. Likewise, beliefs about capabilities (e.g., action-, maintenance- and recovery self-efficacy) are less strong among the inactive group. Even though remote technologies are considered to be helpful [14], e-health coaching services for persons with MS do not seem to be sophisticated enough yet [15] and need to make use of various behavior change techniques to be promising in the long term [13].

We designed a German version of *Activity Matters*, a web-based self-management program that has been developed by Irish researchers and described in detail elsewhere [17]. The primary aim of this paper is to describe the development process of the German version, test feasibility and present the results of the process evaluation of the pilot study.

Methods

The development, feasibility testing and pilot study of the German version of *Activity Matters* is part of a multiphase, mixed-methods study covering the first two phases of the Medical Research Council (MRC) framework to develop and evaluate complex interventions [16] (Figure 1).

Ethics

Ethics approval was received from the Hamburg Chamber of Physicians (PV7349).

Intervention development and procedures

Activity Matters is a twelve-week web-based program developed by *Casey et al.* [17]. The development process was guided by the UK's MRC framework for the development and evaluation of complex interventions [18] and the behavior change wheel (BCW) [19]. Table 1 gives an overview of the weekly schedule of *Activity Matters*. The intervention addresses a comprehensive set of constructs including e.g., knowledge, skills, social influences, environmental context and resources, beliefs about capabilities, beliefs about consequences and goals. Corresponding behavior change techniques were

mapped to the constructs (e.g., information provision, goal setting, action planning, problem-solving, focus on past success) [17]. A detailed description can be found in Appendix A.

Program description

Activity Matters encourages participants to engage in a self-chosen PA in their living environment. The web-based program guides participants over twelve weeks, engaging them in eleven "structured modules" [17]. Participants were asked to complete interactive elements such as activity logs and exercise diaries. Apart from the phone calls that were scheduled as standard in the program (Table 1), participants could ask for help at any time of the program by sending an e-mail. If questions could not be clarified *via* mail, a phone call with a member of the study team was arranged. Weekly reminder e-mails were sent to encourage exercise adherence. Throughout the development process of the German version of *Activity Matters* (Figure 1) the original program content was not changed but only translated into German professionally and adapted culturally and to the local circumstances in Hamburg (Germany) (Table 2). Sports facilities and training courses suitable for persons with MS in the metropolitan area of Hamburg or accessible online were ascertained. Criteria for suitable courses were highly qualified trainers and possible adaption of course requirements to special needs of participants. Videos with German persons with MS and MS exercise experts (e.g., a neurologist, a sports scientist and a physiotherapist) were produced and integrated into the program. Persons with MS shared their experiences with PA, and MS exercise experts presented evidence on the beneficial role of PA for symptom management. Research evidence was updated, and lay abstracts of referenced studies in the German language were generated on various MS-related topics such as fatigue, balance or mood. Finally, a German *Activity Matters* website (www.activity-matters.de), accessible for everyone, was created by TAKE PART Media+Science, a digital health communication company. The website shares general information about the project and a password-protected subscriber area, where the adapted program content was uploaded.

Feasibility testing

Participants and recruitment

A convenience sample of eight persons with MS and four MS exercise experts got access to the program for a period of six weeks. Persons with MS were recruited *via* the Hamburg section of the German MS Society (DMSG) as well as from the MS day clinic of the University Medical Center Hamburg Eppendorf (UKE). MS exercise experts were recruited *via* collaborating research groups of the MS day clinic and the DMSG. After providing informed consent, participants of the feasibility testing were provided with login details for the

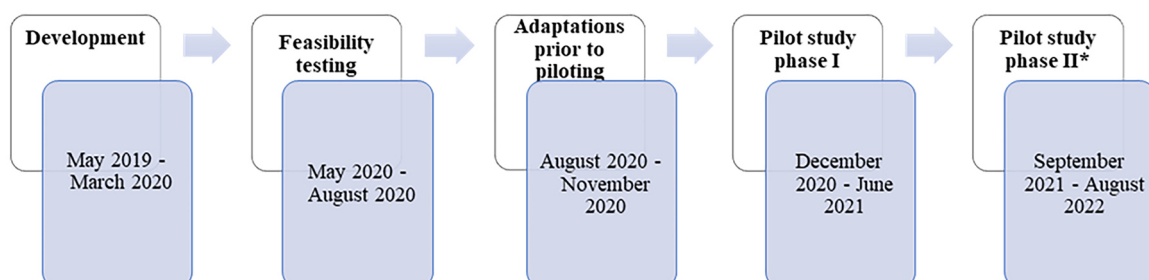


Figure 1. *Activity Matters* development and evaluation process.

*Data are not part of the actual publication.

Table 1. *Activity Matters* program description based on Casey, 2018 [17].

	Weekly outline	Corresponding program components	Week number
Module 1	Benefits of PA	<ul style="list-style-type: none"> • Written information • Videos 	1
Module 2	Goal-setting	<ul style="list-style-type: none"> • Activity log • SMART goals • Written information • Videos 	1
Module 3	Choosing the right activity	<ul style="list-style-type: none"> • Written information • Videos 	2
Module 4	Action planning	<ul style="list-style-type: none"> • SMART goals and feedback from the study team • Exercise plan • Activity log 	2
Module 5	Self-monitoring	<ul style="list-style-type: none"> • Written information • Exercise plan • Activity log 	3
Module 6	Barriers and symptom management	<ul style="list-style-type: none"> • Written information • Videos • Exercise plan • Activity log 	4
Module 7	Social support	<ul style="list-style-type: none"> • Written information • Chat Group • Videos • Exercise plan • Activity log 	5
Module 8	Self-talk and exercise diary	<ul style="list-style-type: none"> • Written information • Exercise diary and feedback from the study team • Exercise plan • Activity log 	6
No Module	Remaining active	<ul style="list-style-type: none"> • Phone call with the study team • Exercise plan • Activity log 	7
Module 9	Having a bad day and goal revision	<ul style="list-style-type: none"> • Written information • Videos • SMART goals and feedback from the study team • Exercise plan • Activity log 	8
No Module	Remaining active	<ul style="list-style-type: none"> • Phone call with the study team • Exercise plan • Activity log 	9
Module 10	Maintaining the behavior	<ul style="list-style-type: none"> • Written information • SMART goals • Exercise plan • Activity log 	10
No Module	Remaining active	<ul style="list-style-type: none"> • Exercise plan • Activity log 	11
Module 11	Future outlook	<ul style="list-style-type: none"> • Written information 	12

password-protected area of the *Activity Matters* website and an accompanying questionnaire.

Feasibility outcomes

The feasibility questionnaire (Appendix B) addressed five of the consolidated categories of evaluation criteria for digital health interventions by Kowatsch et al. [20]: participant demographics, ease of use, adherence, content quality and perceived benefit. The questionnaires consisted of open and closed questions, mostly assessed on six-point Likert scales. Participants were allowed to provide additional information through free text for some of the closed questions. Subsequently, semi-structured telephone interviews were conducted to receive more detailed information based on the information gathered in the filled-in questionnaires.

Data analysis

Responses to closed questions were analyzed using descriptive and inductive statistics. Continuous variables were described using

Table 2. Adaptations for the German version of *Activity Matters*.

Irish Version	German Version
English Content	Content was not changed but just translated
English Videos with pwMS and MS experts	Production of Videos in German language. Topics remained similar to the Irish version: Five pwMS talked about their experiences with yoga, walking, fatigue and social support and three MS experts informed about the effect of PA, yoga, walking and the Uthoff phenomenon.
Training courses of the Irish MS patient organization in different locations	Suitable sports facilities and training courses in the Metropolitan Area of Hamburg were added to the content: <ul style="list-style-type: none"> • Exercise courses offered by the Hamburg MS patient organization • Certified prevention sport courses financially supported and offered by statutory health insurance • Rehabilitation sports courses • Inclusive sports offers • Online training courses for pwMS
Facebook group for interaction among participants	MS Connect (social network tool of the DMSG)
Research evidence	Update of research evidence and provision of lay abstracts.

median and range, and categorical variables were expressed as absolute and relative frequencies. Responses to open questions in the questionnaires and the recorded telephone interviews were independently reviewed by two researchers (KRL & ND). Instead of using formal thematic analysis, the received feedback was clustered to themes. This allowed us to extract information about necessary revisions of the program. The results were discussed between the two researchers and within the Hamburg research group to deliberate on changes to be made in the program prior to piloting: we added short introductions of the study team members, increased the difficulty of the quizzes and made the references to sports opportunities more prominent.

Pilot study

The pilot study pursues a pre-post, single-group, repeated measures intervention design. Due to restrictions for sports facilities caused by the Sars Cov-2 pandemic in Germany throughout Pilot study phase I and the limited case number achieved, we decided to extend the timeframe of the study to test *Activity Matters* in a phase without restrictions (Pilot study phase II). Preliminary information on the efficacy of the intervention for changing PA behavior from phase 1 will be provided. A subsequent report will address the efficacy of behavioral and symptom-related changes.

Participant recruitment

Participants were introduced to the study during their regular appointments at the MS day clinic of the UKE. Additionally, persons with MS, who had participated in a fitness check and had received individualized exercise recommendations by the Center for Athletic Medicine at the UKE, but were not able to adhere to these recommendations, were invited to take part in the study. Moreover, information about the study was provided through press releases, the newsletter of the MS day clinic, social media and the website of the cooperation partners, the Hamburg section of the self-help society (DMSG) and the *Techniker* German health insurance company. Interested persons were provided with the study information and the consent form using the online platform

www.unipark.de. After giving informed consent, participants were guided to eligibility criteria and the baseline survey. Participants were eligible if they were ≥ 18 years old and lived in the metropolitan area of Hamburg. Participants needed to self-report a diagnosis of MS of any subtype and confirm a Patient Determined Disease Steps score (PDDS) [21] of < 6 , which means that they could walk without a walking aid or only used one cane or crutch for constant walking support. Participants provided information to ensure there were no safety concerns regarding PA due to general illnesses, or that these had been clarified with a physician prior to participation. Moreover, they needed access to the internet, preferably with a computer, laptop, or tablet. Those who did not meet the eligibility criteria were guided to the end of the survey by skip logic. Eligible persons with MS were given access to the password-protected area of the *Activity Matters* website that guided them through eleven modules within twelve weeks.

Participant characteristics

We collected data on age, sex, marital status, educational background and employment at baseline. We gathered clinical data on the subtype of MS, year of diagnosis, disability using the PDDS [22] and if they had a relapse in the last three months. We surveyed participants' internet usage patterns, sports experiences and prior knowledge about PA and MS to inquire about their preconditions.

Process evaluation

The participants were asked to answer questions about their program experiences. The questionnaires (Appendix C) were sent out after six weeks and after finishing the program. To receive the follow-up questionnaire, at least five modules had to be processed within a time frame of twelve to 18 weeks. Participants who completed less than five modules were considered as drop-outs. Drop-outs were asked to give reasons for quitting the program. The questionnaires were constructed following criteria by Kowatsch [20] relating to the following categories: ease of use, adherence, content and service quality and perceived benefit. Additionally, we asked for recommendations for further development of the program and we sought information about the usage of online sports options in times of Covid-19. The items varied between closed, mostly six-point Likert scales and open questions.

PA outcomes

GLTEQ health contribution score. At baseline and after program completion PA was measured with the *Godin Leisure Time Questionnaire (GLTEQ)* [23]. *GLTEQ* is a three-item self-administered questionnaire [24] that has shown validity in people with MS [25, 26] to determine usual PA practiced for more than 15 min during leisure time in a typical week [25]. The questionnaire seeks information on the average units of strenuous (e.g., jogging), moderate (e.g., fast walking) and mild (e.g., easy walking) [25] activities. By using the following formula an overall *GLTEQ Score* can be calculated: weekly leisure-time activity score (*GLTEQ Total Score*) = $(9 \times \text{Strenuous}) + (5 \times \text{Moderate}) + (3 \times \text{Mild})$ [23]. In order to categorize the activity levels, Godin proposes to compute the *GLTEQ Health Contribution Score* by taking into account only strenuous and moderate activities using the following formula: *GLTEQ Health Contribution Score* = $(9 \times \text{Strenuous}) + (5 \times \text{Moderate})$ [27]. From the resulting *GLTEQ Health Contribution Score*, participants can be subdivided into three groups: *active* (≥ 24 units), *moderately active* (14–23 units) and *insufficiently active* (< 14 units) [27].

Nigg's PA staging questionnaire. We used *Nigg's PA Staging Questionnaire* [28] to identify different stages of behavior concerning regular PA. Regular PA was defined in this study as at least 30 min of exercise four times per week, for example, through fast walking or cycling. The questionnaire originally uses four questions and an algorithm to classify participants into five stages of change: *Pre-Contemplation*, *Contemplation*, *Preparation*, *Action* and *Maintenance*. As described before [13] we extended the original questionnaire by a fifth question about activity during the past twelve months and added the category *Long-term maintenance*. According to previous research [13] we downsized the number of categories into three: *Pre-Contemplation*, *Contemplation* and *Preparation* resulted in the new category *Not regularly active*, *Action* and *Maintenance* were combined into *Currently regularly active* and the last category was retained *Long-term regularly active*.

Data analysis

Responses to closed questions were analyzed using descriptive statistics. Continuous variables were described using mean and standard deviation or median and range, whereas categorical variables were expressed as absolute and relative frequencies. The effect size (*Cohen's d*) for changes in PA was calculated for *GLTEQ Total Score*. For comparing baseline *GLTEQ* value with post intervention *GLTEQ* value, a paired t-test was determined. For the evaluation of *Nigg's PA Staging Questionnaire*, the number of participants in different stages of behavior were compared pre- and post-intervention. IBM (International Business Machines Corporation) SPSS Statistics 26.0 was used for the analysis. Responses to open questions were reviewed by two researchers (KRL & ND), semi-structured telephone interviews were recorded by IB and ND and independently analyzed.

Results

Feasibility testing

In total, eight persons with MS and four MS exercise experts from different disciplines (two sports scientists, one rehab scientist and one physiotherapist) participated in the feasibility testing in summer 2020. Participant characteristics are shown in Table 3.

Feasibility testing with persons with MS

The surveyed categories and dimensions with corresponding Likert anchors are listed in Table 4. Ease of use was evaluated for the baseline survey and the *Activity Matters* program.

Feasibility of the survey. Answering the baseline survey, provided online via www.unipark.de, was considered easy by all eight persons with MS. On average it took them 17 min to fill in the form. The comprehensibility of the survey was rated as high and the extent of the survey was considered reasonable.

Feasibility of the program. Three of eight persons with MS experienced technical issues with the *Activity Matters* program, e.g., with sending in activity logs or navigating through the website. The median number of modules viewed by participants was eleven, although the range was relatively wide (R 2–11). Six participants processed all eleven modules, one participant considered five modules and one considered two. Participants reported having worked very intensively on the modules. By using a school grade format ranging from one (*very good*) to six (*insufficient*), *Activity Matters* was graded as good, three

Table 3. Participant characteristics - feasibility testing.

	Persons with MS (n=8)	MS exercise experts (n=4)
Sex (female)	5	3
Age (Mdn, R)	55 (29–73)	29.5 (26–37)
Education		
Primary / secondary degree	2	–
High school degree	5	4
Others	1	–
Disease course		
RRMS	2	
SPMS	4	
PPMS	1	
Unknown	1	
Years since diagnosis (Mdn, R)	17.8 (0.3–29.6)	
Profession		
Researcher		3
Practitioner		1
Self-assessed MS knowledge		
Low		–
Medium		2
High		2

Data shown as frequencies if not specified differently.
Median (Mdn), Range (R), Relapsing-remitting MS (RRMS), Secondary progressive MS (SPMS), Primary progressive MS (PPMS).

persons with MS perceived the program as satisfactory (grade 3). Answers given to the open question about the overall impression of *Activity Matters* confirm a high acceptance of the program. One participant referred to the variability of given sports options in the program:

I liked that each participant decides for him- or herself what, how much and when to do something. (AM_029, person with MS, 21 years since diagnosis)

The extent of the modules was rated as reasonable and the comprehensibility of the content was also confirmed. Four persons with MS expressed wishes for further development for *Activity Matters* concerning long-term follow-ups and comprehensive feedback from the study team. They proposed the following:

Personal assistance with goal setting. (AM_030, person with MS, 7 years since diagnosis)

A follow-up after the 12 weeks in the form of questions about staying active and, if necessary, new motivation at longer intervals. (AM_029, person with MS, 21 years since diagnosis)

The program's content was rated as highly relevant for persons with MS in general. When asking the eight persons with MS about the relevance for them personally, the range of answers showed greater variation and the median score was lower. The program was evaluated as motivating and the videos were thought to be motivating and helpful. As previously anticipated in the free text responses about the overall impression of the program, *Activity Matters* was considered moderately encouraging to plan changes in their PA by the feasibility participants. In accordance with the overall positive feedback for *Activity Matters*, all participants would recommend it to other persons with MS. *Activity Matters* was assessed as a helpful tool to support changes in PA behavior among persons with MS:

Because I know from my own experience how well exercise can relieve symptoms and I also know that you can use all the support you can get to start making changes. (AM_029, person with MS, 21 years since diagnosis)

Finally, we wanted to know what the participants liked and disliked most about *Activity Matters*. We received positive feedback

Table 4. Results of the feasibility testing.

Categories	Dimension	Persons with MS (n=8) Mdn (R)	MS Exercise Experts (n=4) Mdn (R)
Ease of use	Comprehensibility of the questionnaire	5.0 (3–5)	n.a.
	1 not at all understandable – 6 very understandable		
Adherence	Appropriateness of the questionnaire's extent	5.0 (3–5)	n.a.
	1 not at all appropriate – 6 very appropriate		
Content quality	Intensity of dealing with the program	5.0 (3–5)	4.5 (3–5)
	1 not at all intensive – very intensive		
Perceived benefit	Comprehensibility of the program	5.0 (3–5)	5.0 (5–6)
	1 not at all understandable – 6 very understandable		
Perceived benefit	Appropriateness of the extent of the modules	5.0 (2–6)	5.0 (4–6)
	1 not at all appropriate – 6 very appropriate		
Perceived benefit	Relevance of the program for persons with MS	6.0 (4–6)	6.0 (6)
	1 not at all relevant – 6 very relevant		
Perceived benefit	Relevance of the program for the participant personally	4.5 (3–6)	n.a.
	1 not at all relevant – 6 very relevant		
Perceived benefit	Motivational value of the program	4.0 (3–5)	5 (4–6)
	1 not at all motivating – 6 very motivating		
Perceived benefit	Motivational value of the videos	5.0 (3–6)	5.0 (3–6)
	1 not at all motivating – 6 very motivating		
Perceived benefit	Inspiration to plan change in PA	3.5 (1–6)	n.a.
	1 No, not at all – 6 Yes, very much		
Perceived benefit	Likelihood of recommending the program to others	6.0 (4–6)	5.5 (5–6)
	1 No, definitely not – 6 Yes, in any case		

Median (Mdn), Range (R), not applicable (n.a.).

about the program's opportunities for interaction (e.g., sending in self-set goals and weekly activity logs). Besides, one participant also referred to the structure of the program and emphasized certain individual program components to be especially helpful:

That there were also modules for taking a break sometimes and that enough space was given to the 'bad days', the motivational issues. (AM_027, person with MS, 21 years since diagnosis)

Nevertheless, there were also components of the program which participants found less helpful or reasonable (e.g., quizzes or the chat group).

Feasibility testing with MS exercise experts

Three of four experts were female. The group had a median age of 29 years. Two of the exercise experts self-assessed their expertise in MS as high, two as medium. All of the four experts confirmed ease of use as none of them experienced any technical issues with *Activity Matters*. The median number of considered modules was eleven. Three experts viewed all eleven modules, one processed eight (R 8–11). They did not deal as intensively with the content as the persons with MS. The experts also rated the program with a school grade of two, although one expert expressed doubts about the program's effectiveness:

The program seems well thought out, has a great interface, is consistent with the state of the art in terms of content and overall seems very professional. What remains debatable for me is to what extent it will encourage persons with MS to exercise more. (AM_023, MS exercise expert)

The experts also rated the extent of the modules and the comprehensibility of the program as appropriate. All four MS exercise experts rated the program's content as highly relevant for persons with MS. The program was seen as very motivating and the videos were rated to be motivating and helpful, too. All experts would recommend the program to MS patients.

Appendix D and Appendix E contain further illustrative quotes gathered during the telephone interviews (n = 12).

Adaptations after feasibility testing

Based on the received feedback, we included members' portraits of the study team on the website and added the information of an option to be called by the team in case of questions or uncertainties more frequently. In order to equalize content and make the modules similarly comprehensive, some texts were moved to other parts of the program. In response to the ongoing Covid-19 pandemic, online sports services and notes on safety and hygiene measures were also incorporated into the program.

Pilot study

Participants

43 participants started the program, four (9%) dropped out early and 36 (84%) participated in the post intervention survey. Figure 2 illustrates the flow of participants, including reasons for declining during the study. Participant demographic data are shown in Table 5. Participants were mostly women (81%) and had a mean age of

49.5 years (*SD* 9.29). 31 of 43 (72%) had a high school degree. More than half (56%) had a relapsing-remitting course of MS, the mean PDDS was 2.2 (*SD* 1.47). Motivation to participate included interest in the study, wanting to learn about PA and MS and wanting to contribute to MS research. Participants rated their MS knowledge as moderate, however most of them had already informed themselves about PA and MS. For more details about the preconditions of the participants see Appendix F.

Process evaluation

In order to achieve a concise presentation of the results, we primarily present the results of the process evaluation after program completion. The results of the earlier process evaluation after six weeks can be found in Appendix G. Thirty-six of 43 participants took part in the follow-up survey after program completion. The surveyed categories and dimensions with corresponding Likert anchors are listed in Table 6.

Sixty-six percent (23 of 35) logged in to the *Activity Matters* program at least once a week, 34% (12 of 35) once a month or less. Twenty-seven dealt with each of the eleven modules, four worked through eight to ten modules, and five through two to seven modules. On average, 9.8 modules were processed and participants stayed into the program for 13 weeks. The amount of time spent on *Activity Matters* was considered reasonable or moderate. The extent of the modules was considered appropriate. Being an online-only program, the study team gave feedback or helped the participants mostly via e-mail and, if wished for, also by phone. To find out more about the desire of interaction, we asked if there was enough contact to the study team and how helpful their assistance was. Twenty-five of 36 (69%) considered the contact with the team sufficient. Those who felt insufficiently supervised suggested the following:

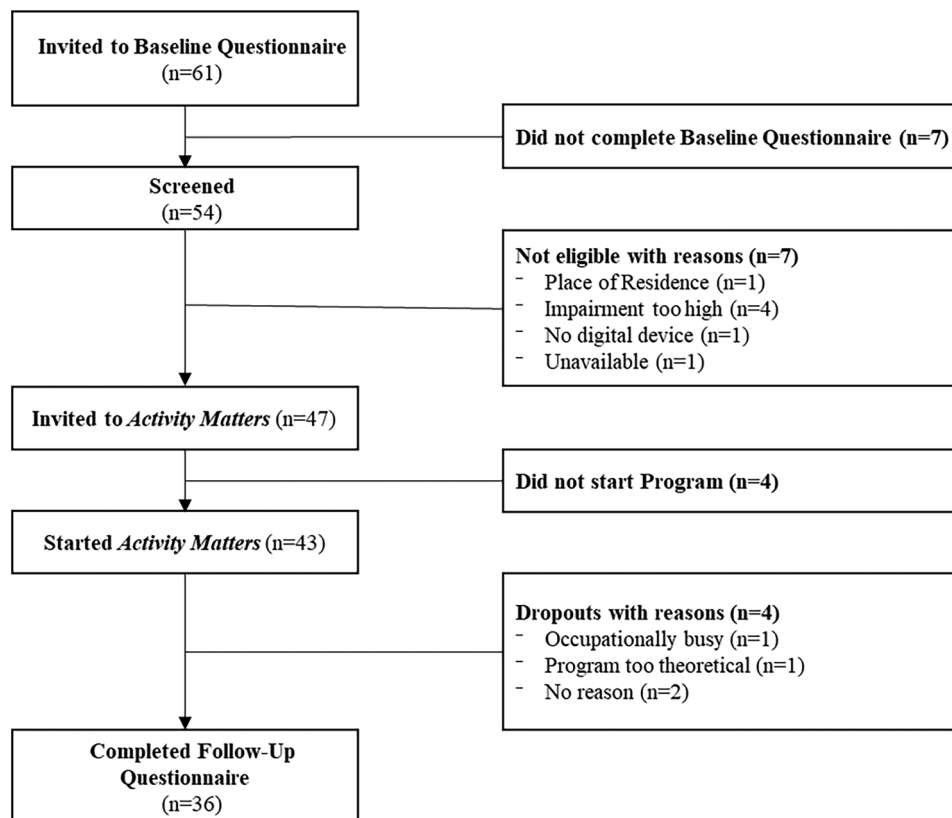


Figure 2. Participant flow diagram.

Table 5. Participant characteristics - Pilot study.

	Persons with MS (n=43)
Sex (female)	35 (81.4)
Age (M, SD)	49.5 (9.29)
Education	
primary/secondary degree	12 (27.9)
high school degree	31 (72.1)
Marital status	
Single	7 (16.3)
Married / cohabitating with a partner	30 (69.8)
Divorced	4 (9.3)
Widowed	1 (2.3)
Not specified	1 (2.0)
Employment	
Employed full time	11 (25.6)
Employed part time	17 (39.5)
Apprenticing	2 (4.7)
Unemployed	2 (4.7)
Retired due to medical reasons or disability	10 (23.3)
Retired due to age	1 (2.3)
Disease course	
RRMS	24 (55.8)
SPMS	6 (14.0)
PPMS	6 (14.0)
Unknown	7 (16.3)
Years since diagnosis (M, SD)	13.2 (8.86)
PDDS (M, SD)	2.2 (1.47)
Did you have a relapse in the past three month?	
Yes	2 (4.7)
No	41 (95.3)

Data shown as frequencies with percentage in brackets if not specified differently.

Mean (M), Standard deviation (SD).

Table 6. Results of the pilot study - process evaluation.

Categories	Dimension	Persons with MS Mdn (R)
Ease of use	Time expenditure for the program (n=35) 1 very little – 6 very high	3.0 (1–6)
Content and service quality	Appropriateness of the extent of the modules (n=35) 1 not at all appropriate – 6 very appropriate	5.0 (2–6)
	Feedback of the <i>Activity Matters</i> team (n=34) 1 not at all helpful – 6 very helpful	4.0 (1–6)
	Motivational value of the program (n=33) 1 not at all motivating – 6 very motivating	5.0 (1–6)
Perceived benefit	Likelihood of recommending the program to others (n=35) 1 No, absolutely not – 6 Yes, in any case	5.0 (1–6)

Median (Mdn), Range (R).

More interaction by e-mail or even a personal conversation at the beginning. (AM_079, 16 years since diagnosis)

After I had not continued for several weeks, I would have liked to have been given encouragement first in written form and perhaps in a follow-up conversation, or to have been offered a motivational talk. That offer was missing. (AM_070, 26 years since diagnosis)

Personal support, chat group maybe via Zoom on a specific date, direct interaction. (AM_092, 8 years since diagnosis)

The contact to the study team whenever participants had questions concerning their training or technical issues was seen as helpful. Participants were invited to give further comments on the program's content:

Thematically well structured, understandable and motivating when you need help to become active. Not too overwhelming. (AM_057, 22 years since diagnosis)

Listing all components (Table 1) of *Activity Matters*, we gathered information about which of the given tools the participants considered to be most helpful. Participants stated that they benefited most from setting up exercise plans, the activity logs, which they were asked to write down every week, setting SMART goals and reading the written information. The videos showing experts and MS patients were thought to be moderately helpful. The interaction with other participants in the chat group was not considered helpful. See Figure 3 for detailed results of the survey questions.

After six weeks, eleven of 26 participants, who filled in the corresponding survey at half of the program, used online sports services for exercising. Most (ten of eleven) stated to have viewed courses shown in *YouTube* videos. Others used fitness apps on their smartphones or online classes they had visited in person before. About half of the participants (19 of 36) stated that they had also used online sports options during the program's second half. Mentioned online courses were, among others, a functional training held by the DMSG, workouts in *YouTube* videos and an online meditation course. Participants were asked to provide feedback on what they would like to see in the further development of *Activity Matters*. Interpreting the given answers, personal contact and more specific exercise suggestions are the most apparent.

Online yoga classes or something similar for practicing at home. (AM_101, 28 years since diagnosis)

Feedback on activities. Accessible design for the visually impaired, e.g., a read-aloud function for the modules or graphically improved labelling of the videos. (AM_074, 21 years since diagnosis)

All in all, participants would recommend *Activity Matters* to other persons with MS (Mdn 5.0, R 1–6):

I realized the following: Counting my steps on a pedometer is already better than lying in bed. For me, I started *Activity Matters* at exactly the right time. (AM_096, 15 years since diagnosis)

The online program feels much more personal than I would have expected. (AM_050, 29 years since diagnosis)

Appendix H shows further quotes gathered from the telephone interviews (n = 5).

Change in PA behavior (pre/post, n=36)

Physical activity, as measured with *GLTEQ*, increased significantly from pre- to post intervention with a mean *GLTEQ Total score* of 26.19 (SD 23.40) at baseline to 34.97 (SD 20.24) in the follow-up (*p-value* 0.042). The effect size (*Cohen's d*) is 0.35. Improvements in moderate to vigorous physical activity as measured with *GLTEQ Health Contribution Score* were also detectable: While the number of insufficiently and moderately active participants each decreased, the number of participants classified as active increased by seven persons (Table 7). Similarly, more participants increased their regular physical activity as measured with the *Nigg's PA Staging* and moved to the currently or long-term active stages of change (Table 7).

Discussion

This paper describes the development, feasibility testing and process evaluation of the German version of *Activity Matters* using the MRC framework. This framework has been successfully used

To what extent have the following components of *Activity Matters* helped you increase your physical activity?

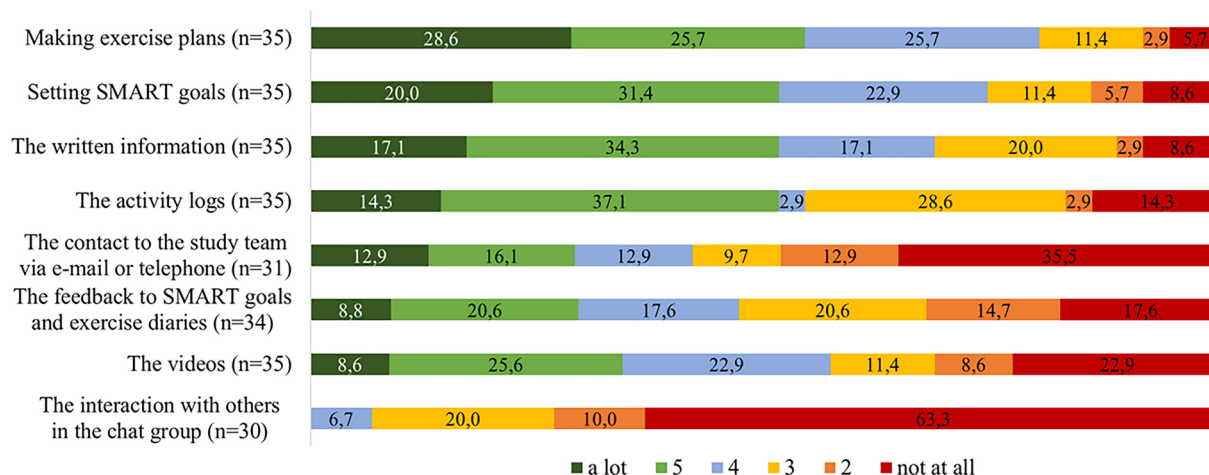


Figure 3. Participant responses to process evaluation survey post intervention, data shown as percentages.

Table 7. GLTEQ Health Contribution Score and Nigg's PA Staging from baseline to post intervention.

	GLTEQ Health Contribution Score (n=36)		
	Insufficiently active	Moderately active	Active
Baseline	17	8	11
Post Intervention	11	7	18

	Nigg's PA Staging (n=35)		
	not regularly active	currently regularly active	long term regularly active
Baseline	23	6	6
Post Intervention	14	9	12

Godin Leisure Time Exercise Questionnaire (GLTEQ).

in other studies by the research group [29–31] and aligns well with recent guidance by *Motl* et al. to move through the continuum of the stages of research to collect knowledge and experiences that will inform the execution of efficacy and effectiveness studies [32]. In our study, feasibility testing allowed for modifications of the initially developed program to the needs of persons with MS before starting the pilot study. Moreover, the results of the process evaluation can be used to improve the program before starting a definite RCT. In this study we also used the results of the process evaluation to improve the program before starting Pilot study phase II, e.g., by offering video conferences moderated by the study team to create more interaction during Pilot study phase II. This second phase had not been planned in advance but was scheduled after Pilot study phase I was carried out under lockdown conditions due to the Sars Cov-2 pandemic.

Overall, the *Activity Matters* intervention was feasible and well accepted by both, MS exercise experts and persons with MS. This is in line with previous research that showed that using technology for information provision [33] or lifestyle advice [30] is often used and well accepted by persons with MS. Results of the process evaluation show that most components of the program were rated to be appropriate and helpful. Participants in this study perceived knowledge provision through written information and videos as well as action planning, goal setting and self-monitoring through activity logs as most helpful for increasing their physical activity. This is in line with previous research showing that these behavior change techniques are among the most frequently used

in successful PA interventions among persons with MS [34]. The results also support the theory-based development process of *Activity Matters*, which identified information provision using credible sources and strengthening the participants' capability through action planning, goal setting and review of behavioral goals as important strategies within the program [17].

Some participants (eleven of 36) felt insufficiently supervised by the study team and expressed the wish for more personal contact and support. Though the program consistently offered additional telephone calls to the study team in the event of difficulties or questions, this was rarely taken up. Compared to other behavior change interventions summarized by *Coulter* et al. [35] that included face to face counseling, supervised training sessions, chat sessions and video coaching, the amount of personal contact in this study was very limited which seems to be an issue for a subset of participants. The rationale behind *Activity Matters*, however, is to encourage persons with MS to find a form of activity that suits them and to get peer and trainer support in the community. This approach was chosen to avoid the difficulties that arise when implementing exercise studies conducted in clinical settings in real world settings [32]. While the free choice of the activity was very much appreciated by some participants, for others this might have been especially difficult under lockdown restrictions when peer and trainer support was very limited. Hence, the consequences of the Sars Cov-2 pandemic for participation might have added to the feeling of insufficient support among some of the study participants. Moreover, unlike other programs that specify exercises and often have them performed under supervision [35], *Activity Matters* might require higher levels of self-management skills that some participants may not have had.

Many study participants did not strictly adhere to the twelve-week plan and thus stayed longer in the program or completed it at their own pace. Hence, individualization of the program to the needs and preconditions of the participants seems relevant for future developments. After finishing pilot study phase II (Figure 1) we will make in depth analyses to possibly identify participant baseline characteristics that make successful participation in *Activity Matters* more or less likely.

Preliminary results of the pilot study phase I show an increase in mean PA from pre- to post intervention with a small effect size. According to self-report, more participants were regularly

active post intervention and less were insufficiently active as measured with the *GLTEQ Health Contribution Score*. These are promising results that will be fully evaluated after finishing pilot study phase II and need to be verified in a definite RCT.

Study limitations

The study findings are limited by the fact that the majority of participants were recruited at the UKEs MS day clinic in Hamburg. However, we have no indication that persons with MS from Hamburg generally face different challenges to become active than those from other parts of Germany. Some participants had already participated in sports related research involving a fitness check and individual exercise advice at the clinic before, but only the ones that had been unsuccessful in increasing their exercise level have been invited to take part in this study. The findings of the process evaluation are based on the feedback provided by 36 of 43 participants and five interviews. Therefore, we cannot rule out that those with missing data or those not interviewed would have judged the program differently.

The study design did not include a control group, so future research remains necessary to confirm or refute the promising increase in PA levels in this study. Moreover, PA was only measured by self-report but not confirmed by objective measurement. While this is a common feature of online interventions, research shows that self-report levels are usually higher than objectively measured PA [36].

Conclusions

Most participants were pleased with the program and a considerable proportion of participants were able to increase their level of PA or stay physically active even under the challenging conditions of a Sars Cov-2 lockdown. Individualization of the program to the needs (e.g., in terms of contact and support) and preconditions of the participants seems relevant for future developments.

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2. Darstellung der Publikation

2.1 Einleitung

Multiple Sklerose (MS) ist eine chronisch entzündliche Autoimmunerkrankung, die mit Demyelinisierungen im zentralen Nervensystem einhergeht. Mit einer Prävalenz von 240.000 Betroffenen in Deutschland (1), stellt die MS eine Hauptursache für körperliche Behinderungen bei jungen Erwachsenen dar (2,3). Ein Faktor, der Personen mit MS helfen kann, ihre Fitness und Mobilität zu verbessern, MS Symptome zu lindern und die gesundheitsbezogene Lebensqualität der Betroffenen zu erhöhen, besteht in der Steigerung der körperlichen Aktivität (4,5). Entsprechend der Empfehlungen für die gesunde Population, wird es auch Menschen mit MS nahegelegt, sich für mindestens 150 Minuten pro Woche in Form von sportlicher Anstrengung oder Alltagsaktivitäten körperlich zu betätigen (5). Studienergebnisse (6,7) belegen jedoch, dass Menschen mit MS in ihrem Lebensumfeld auf lokale und strukturelle Barrieren stoßen, die sie daran hindern können, regelmäßig körperlich aktiv zu sein. MS Patient:innen, insbesondere solche mit fortgeschrittener Behinderung, scheinen einen ungedeckten Bedarf an verfügbaren, qualitativ hochwertigen und variablen Sportprogrammen zu haben. Darüber hinaus scheinen Online-Gesundheitsdienste für Menschen mit MS noch nicht ausgereift genug zu sein (8), wengleich sie von ebensolchen profitieren könnten (9).

Zu diesem Zwecke wurde eine deutsche Version von *Activity Matters* entwickelt. *Activity Matters* ist ein zwölfwöchiges, webbasiertes und verhaltenswissenschaftlich fundiertes Selbstmanagementprogramm, das von irischen Forscherinnen entwickelt wurde (10). Das Hauptziel der Publikation war es, den Entwicklungsprozess der deutschen Version zu beschreiben, die Machbarkeit des übersetzten und angepassten Programms zu testen und die Ergebnisse der Prozessevaluation der Pilotstudie zu präsentieren.

Die Entwicklung, Machbarkeitstestung und Pilotstudie der deutschen Version von *Activity Matters* ist Teil einer mehrphasigen, methodengemischten Studie, die die ersten beiden Phasen des Medical Research Council (MRC) Frameworks zur Entwicklung und Bewertung komplexer Interventionen abdeckt (11). Die Intervention basiert auf einer Reihe von Indikatoren zur Verhaltensänderung, darunter zum Beispiel die Aneignung von Wissen, soziale Einflüsse, das Bewusstsein über die eigenen Fähigkeiten sowie das Setzen erreichbarer Ziele. Diesen Indikatoren wurden entsprechende Techniken und Ressourcen zugeordnet (zum Beispiel durch Bereitstellung von Informationen, Hilfe bei der Zielsetzung, Anleitung zum Erstellen von Bewegungsplänen und Techniken zur Problemlösung) (10). *Activity Matters* ermutigt die Teilnehmer:innen, eine selbst gewählte körperliche Aktivität in ihrem Lebensumfeld auszuführen, indem das webbasierte Programm sie über einen Zeitraum von zwölf Wochen durch elf strukturierte Module leitet (10). Währenddessen sollen die Teilnehmer:innen interaktive Elemente, wie Aktivitätsprotokolle und Bewegungstagebücher, führen.

Der ursprüngliche Programminhalt wurde nicht verändert, sondern lediglich professionell ins Deutsche übersetzt und an die kulturellen und lokalen Gegebenheiten in Hamburg angepasst (Tabelle 1). Es wurden Sporteinrichtungen und Trainingskurse herausgesucht, die für Personen mit MS im Großraum Hamburg geeignet oder online zugänglich sind. Schließlich wurde eine deutsche *Activity Matters* Webseite (www.activity-matters.de) von TAKE PART Media + Science, einem Unternehmen für digitale Gesundheitskommunikation, erstellt. Die Webseite enthält allgemeine Informationen über das Projekt und einen passwortgeschützten Teilnehmerbereich, in den die angepassten Programminhalte hochgeladen wurden.

2.2 Methoden

2.2.1 Machbarkeitstestung

Eine Stichprobe aus acht Personen mit MS und vier MS- und Sportexpert:innen erhielt über einen Zeitraum von sechs Wochen Zugang zu dem Programm. Die Rekrutierung der MS Patient:innen erfolgte über die Hamburger Abteilung der Deutschen Gesellschaft für Multiple Sklerose (DMSG) sowie über die MS-Tagesklinik des Universitätsklinikums Hamburg Eppendorf (UKE). Die MS- und Sportexpert:innen wurden über kooperierende Forschungsgruppen in Deutschland und über die DMSG rekrutiert. Die Teilnehmenden erhielten Zugangsdaten für den passwortgeschützten Bereich der *Activity Matters* Webseite und einen begleitenden Fragebogen, der Informationen über die Demografie der Teilnehmenden, die Benutzerfreundlichkeit, die Adhärenz, die Qualität der Inhalte und den empfundenen Nutzen des Programms erhob. Anschließend wurden halbstrukturierte Telefoninterviews durchgeführt, um auf Grundlage der Fragebögen präzisere Angaben zu erhalten.

Die Antworten auf die geschlossenen Fragen wurden mit Hilfe von deskriptiver und induktiver Statistik ausgewertet. Kontinuierliche Variablen wurden mit Median und Spannweite beschrieben und kategoriale Variablen wurden als absolute und relative Häufigkeiten ausgedrückt. Die Antworten auf offene Fragen in den Fragebögen und die aufgezeichneten Telefoninterviews wurden unabhängig voneinander von zwei Forscherinnen (Karin Riemann-Lorenz und Nina Daniel) ausgewertet.

2.2.2 Pilotstudie

Die Pilotstudie verfolgt ein Ein-Gruppen Prä-Post-Interventionsdesign. Aufgrund der durch die Sars-Cov-2-Pandemie verursachten Einschränkungen für Sportstätten während der gesamten Pilotstudienphase I und der begrenzten Fallzahl, wurde im Laufe der Intervention beschlossen, den zeitlichen Rahmen der Studie zu erweitern, um *Activity Matters* zusätzlicher in einer Zeit ohne Einschränkungen zu testen (Pilotstudienphase II). Die Publikation beschreibt erste Ergebnisse über die Wirksamkeit der Intervention zur Veränderung der körperlichen Aktivität aus Phase I. Mögliche Teilnehmende wurden bei ihren Terminen in der MS Tagesklinik des UKEs rekrutiert. Außerdem wurden Patient:innen eingeladen, an der Studie teilzunehmen, die zuvor bereits erfolglos versucht hatten, ihre körperliche Aktivität im Forschungsrahmen zu steigern. Um weitere Interessierte zu erreichen, wurden Studieninformationen in Pressemitteilungen des UKEs, im Newsletter der MS Tagesklinik, in den sozialen Medien sowie über die Kooperationspartner, die DMSG und die Techniker Krankenkasse veröffentlicht. Einschlusskriterien zur Studienteilnahme waren ein Mindestalter von 18 Jahren, eine bestätigte MS Diagnose, ein Patient Determined Disease Steps Score (PDDS) (12) von <6 sowie ein Wohnsitz in der Metropolregion Hamburg und ein internetfähiges Endgerät. Teilnehmende, die die Einschlusskriterien erfüllten, wurden zur Eingangsbefragung eingeladen und bekamen im Anschluss Zugangsdaten für den Teilnehmerbereich von *Activity Matters*.

Merkmale der Teilnehmenden

Zu Beginn der Studie wurden Daten zu Alter, Geschlecht, Familienstand, Ausbildung und Beschäftigung erhoben. Es wurden klinische Daten über den MS Verlaufstyp, das Jahr der Diagnose, den Grad der körperlichen Einschränkung unter Verwendung des PDDS (12) gesammelt und erfragt, ob die Teilnehmer:innen in den letzten drei Monaten einen Schub erlitten haben. Darüber hinaus wurden sie zu ihrem Internetnutzungsverhalten, ihren Sporterfahrungen und ihrem Vorwissen über körperliche Aktivität bei MS befragt.

Prozessevaluation

Im Laufe der Studienteilnahme wurden die Teilnehmenden gebeten, Fragen zu ihren Erfahrungen mit dem Programm zu beantworten. Die Einladungen zu den Umfragen wurden nach sechs und zwölf Wochen versendet. Die Fragebögen wurden in Anlehnung an die Evaluierungskriterien für digitale Gesundheitsinterventionen von Kowatsch et al. (13) für die folgenden Kategorien erstellt: Benutzerfreundlichkeit, Adhärenz, Qualität der Inhalte sowie empfundener Nutzen. Darüber hinaus wurde nach Empfehlungen für die Weiterentwicklung des Programms und nach Informationen über die Nutzung von Online-Sportangeboten in Zeiten von Covid-19 gefragt.

Körperliche Aktivität

Die körperliche Aktivität der Teilnehmenden wurde vor der Studienteilnahme und nach Beenden des Programms anhand des Godin Leisure Time Exercise Questionnaires (GLTEQ) (14) und des Nigg Physical Activity Staging Questionnaires (15) erhoben.

Auswertung der Daten

Die Antworten auf geschlossene Fragen wurden mittels deskriptiver Statistik ausgewertet. Kontinuierliche Variablen wurden durch Mittelwerte und Standardabweichung (SD) oder Median und Spannweite beschrieben, während kategoriale Variablen als absolute und relative Häufigkeiten beschrieben wurden. Die Effektgröße (Cohen's d) für Veränderungen der körperlichen Aktivität wurde für den GLTEQ-Gesamtwert (14) berechnet. Für den Vergleich des GLTEQ Health Contribution Scores (14) vor und nach Studienteilnahme wurde ein gepaarter t-Test durchgeführt. Für die Auswertung des Nigg Physical Activity Staging Questionnaires (15) wurde die Anzahl der Teilnehmenden in den verschiedenen Stadien der Verhaltensänderung vor und nach der Intervention verglichen. Die Antworten auf offene Fragen wurden von zwei Mitgliedern des Studienteams (Karin Riemann-Lorenz und Nina Daniel) überprüft, die halbstrukturierten Telefoninterviews wurden von Iris Bruns und Nina Daniel aufgezeichnet und unabhängig voneinander ausgewertet.

2.3 Ergebnisse

2.3.1 Machbarkeitstestung

Insgesamt haben acht Personen mit MS und vier MS Expert:innen an der Machbarkeitstestung teilgenommen und sich mit den Fragebögen und der Programmwebseite befasst. Die Teilnehmenden waren zufrieden mit den Inhalten des Programms und dem Aufwand, der für die Teilnahme an der Umfrage aufgebracht werden musste und vergaben dem Programm durchschnittlich die Schulnote „gut“. Der Programminhalt wurde motivierend und relevant für Personen mit MS empfunden, sodass alle Teilnehmenden der Machbarkeitstestung das Programm an Menschen mit MS weiterempfehlen würden.

2.3.2 Pilot Studie

Das Programm wurde von 43 Personen begonnen, vier Teilnehmende (9%) brachen es vorzeitig ab und 36 Personen (84%) nahmen an der Umfrage nach der Intervention teil. Die Teilnehmenden waren überwiegend weiblich (81%) und hatten ein Durchschnittsalter von 49,5 Jahren (SD 9,29). Von den 43 Teilnehmer:innen hatten 31 Personen (72%) einen Hochschulabschluss. Mehr als die Hälfte (56%) gaben an, an schubförmiger MS erkrankt zu sein; der mittlere PDDS (12) betrug 2,2 (SD 1,47). Tabelle 2 gibt einen Überblick über die demografischen und klinischen Daten der Teilnehmenden.

Sechsendsechzig Prozent (23 von 35) meldeten sich mindestens einmal pro Woche bei *Activity Matters* an, 34% (12 von 35) einmal pro Monat oder seltener. Siebenundzwanzig Personen bearbeiteten jedes der elf Module, vier Teilnehmende schauten sich acht bis zehn

Module an und fünf Personen bearbeiteten zwei bis sieben Module. Im Durchschnitt wurden 9,8 Module bearbeitet und die Teilnehmer:innen benötigten durchschnittlich 13 Wochen für das Programm. Der Umfang der Module wurde ebenfalls als angemessen empfunden. Da es sich um ein reines Online-Programm handelte, gab das Studienteam den Teilnehmer:innen vor allem per E-Mail und auf Wunsch auch per Telefon Feedback oder Hilfestellung. Um mehr über den Wunsch nach Interaktion herauszufinden, wurde gefragt, ob ausreichend Kontakt zum Studienteam bestand und wie hilfreich dessen Unterstützung war. Fünfundzwanzig von 36 Teilnehmenden (69%) fanden den Kontakt mit dem Team ausreichend.

2.3.3 Veränderung der körperlichen Aktivität (prä/post, n=36)

Die mit dem GLTEQ Gesamtwert (14) gemessene körperliche Aktivität nahm durch die Intervention von einem mittleren Wert von 26,19 (SD 23,40) bei Studienbeginn auf einen Wert von 34,97 (SD 20,24) bei der Nachuntersuchung (p-Wert 0,042) signifikant zu. Die Effektstärke (Cohen's d) betrug 0,35. Verbesserungen bei der mittleren bis hohen körperlichen Aktivität, gemessen mit dem GLTEQ Health Contribution Score (14), waren ebenfalls nachweisbar. Während die Zahl der unzureichend und mäßig aktiven Teilnehmer:innen jeweils abnahm, stieg die Zahl der aktiven Teilnehmer:innen um sieben Personen (Tabelle 3). Ebenso steigerten mehr Teilnehmende ihre regelmäßige körperliche Aktivität, die mit dem Nigg Physical Activity Staging Questionnaire (15) gemessen wurde und wechselten in die aktive beziehungsweise langfristig aktive Phase der Veränderung (Tabelle 3).

2.4 Diskussion

Der Artikel beschreibt die Entwicklung, Machbarkeitstestung und Prozessevaluation der deutschen Version von *Activity Matters* unter Verwendung des MRC Frameworks (11), welches in einer Reihe von Studien der Forschungsgruppe (16-18) zuvor erfolgreich eingesetzt wurde und den jüngsten Empfehlungen von Motl et al. entspricht, Wissen und Erfahrungen zu sammeln und in die Durchführung von Wirksamkeits- und Effektivitätsstudien einfließen zu lassen (19). In unserer Studie ermöglichte die Machbarkeitstestung eine Anpassung des ursprünglichen Programms an die Bedürfnisse von Menschen mit MS, bevor mit der Pilotierung begonnen wurde. Darüber hinaus können die Ergebnisse der Prozessevaluation zur Verbesserung des Programms genutzt werden, bevor eine randomisierte kontrollierte Studie durchgeführt wird. Darüber hinaus wurden die Ergebnisse der Prozessevaluation genutzt, um das Programm vor Beginn der Pilotstudienphase II, zum Beispiel durch das Angebot von Videokonferenzen für mehr Interaktion mit dem Studienteam, zu verbessern. Diese zweite Phase war im Voraus nicht geplant, sondern wurde angesetzt, nachdem die Pilotstudienphase I unter Bedingungen der Sars-Cov-2-Pandemie durchgeführt werden musste.

Insgesamt war *Activity Matters* machbar sowie durchführbar und wurde sowohl von den MS- und Sportexpert:innen als auch von den teilnehmenden Menschen mit MS gut angenommen. Die Ergebnisse der Prozessevaluation zeigen, dass die meisten Komponenten des Programms für die Teilnehmenden hilfreich und nützlich waren. Die Teilnehmenden dieser Studie empfanden insbesondere die Wissensvermittlung durch schriftliche Informationen und Videos sowie das Aufstellen der Bewegungspläne, die Festlegung von Zielen und die Selbstbeobachtung durch Aktivitätsprotokolle als hilfreich für die Steigerung ihrer körperlichen Aktivität. Dies deckt sich mit Forschungsergebnissen, die zeigen, dass entsprechende Techniken zu den häufigsten eingesetzten Maßnahmen zur erfolgreichen Förderung der körperlichen Aktivität bei Menschen mit MS gehören (20). Die Ergebnisse unterstützen den theoriebasierten Entwicklungsprozess von *Activity Matters*, der die Bereitstellung von Informationen und die Stärkung der Fähigkeiten der Teilnehmer:innen

durch Bewegungspläne, Zielsetzung und Überprüfung der Ziele als wichtige Strategien innerhalb des Programms identifizierte (10).

Einige Teilnehmende (elf von 36) fühlten sich nicht ausreichend vom Studienteam betreut und äußerten den Wunsch nach mehr persönlichem Kontakt. Obwohl im Rahmen des Programms immer wieder zusätzliche Telefonate mit dem Studienteam angeboten wurden, wurde dies nur selten in Anspruch genommen. Im Vergleich zu anderen, von Coulter et al. (21) zusammengefassten, Interventionen zur Verhaltensänderung, die persönliche Beratung, betreute Trainingseinheiten, Chat-Sitzungen und Video-Coaching beinhalteten, war der persönliche Kontakt in dieser Studie sehr begrenzt. Für einen Teil der Teilnehmer:innen scheint dies nicht ausgereicht zu haben. Der Grundgedanke hinter *Activity Matters* ist jedoch, Menschen mit MS zu ermutigen, eine Form der Aktivität zu finden, die zu ihnen passt und Unterstützung durch ihr soziales Umfeld und Trainer:innen zu erhalten. Während die freie Wahl der Aktivität von einigen Teilnehmenden positiv anerkannt wurde, könnte dies für andere unter Lockdown Bedingungen besonders schwierig gewesen sein. So könnten die Konsequenzen der Sars-Cov-2-Pandemie das Gefühl unzureichender Unterstützung bei einigen Studienteilnehmenden verstärkt haben. Darüber hinaus könnte *Activity Matters* im Gegensatz zu anderen Programmen, die Übungen vorgeben und diese oft unter Aufsicht durchführen ließen (21), ein höheres Maß an Selbstmanagementfähigkeiten erfordern, über das einige Teilnehmende möglicherweise nicht verfügten.

Viele Studienteilnehmer:innen hielten sich nicht strikt an den Zwölf-Wochen-Plan und verweilten länger im Programm oder absolvierten es in ihrem eigenen Tempo. Daher scheint eine Individualisierung des Programms auf die Bedürfnisse und Voraussetzungen der Teilnehmenden für künftige Entwicklungen relevant zu sein. Laut Selbstauskunft waren, gemessen mit dem GLTEQ Health Contribution Score (14), mehr Teilnehmende nach der Intervention regelmäßig aktiv und weniger unzureichend aktiv. Diese vielversprechenden Ergebnisse müssen nach Abschluss von Pilotphase II vollständig ausgewertet und in einer randomisierten kontrollierten Studie überprüft werden.

2.5 Schlussfolgerungen

Die meisten Teilnehmenden waren mit dem Programm zufrieden und ein beträchtlicher Anteil von ihnen war in der Lage, die körperliche Aktivität zu steigern oder unter den erschwerten Bedingungen der Sars-Cov-2 Restriktionen körperlich aktiv zu bleiben. Die Individualisierung des Programms auf die Bedürfnisse und Voraussetzungen der Teilnehmenden bleibt für künftige Erhebungen entscheidend.

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2.7 Anhang

Tabelle 1: Änderungen und Anpassungen für die deutsche Version von *Activity Matters*

Irische Version	Deutsche Version
Englische Inhalte	Die Inhalte wurden nicht verändert, sondern lediglich ins Deutsche übersetzt
Englische Videos mit Personen mit MS und MS- und Sportexpert:innen	Erstellen von Videos in deutscher Sprache. Die Themen blieben erhalten: Fünf Personen mit MS berichteten über ihre Erfahrungen mit Yoga, Walking, Fatigue und sozialer Unterstützung. Drei MS- und Sportexpert:innen informierten über die Effekte von körperlicher Aktivität, Yoga, Walking und über das Uthoff Phänomen.
Sportkurse der MS Patientenorganisation Irland an unterschiedlichen Orten	Passende Sportangebote und Trainingskurse in der Metropolregion Hamburg wurden zum Programm hinzugefügt: <ul style="list-style-type: none"> - Trainingskurse der DMSG - Krankenkassengeförderte zertifizierte Präventionskurse - Inclusive Sportangebote - Online Trainingskurse für Menschen mit MS
Facebook Gruppe für Interaktion zwischen den Teilnehmenden	MS Connect (soziales Netzwerk der DMSG)
Forschungsergebnisse	Übersetzte und überarbeitete Forschungsergebnisse wurden für Laien verständlich zur Verfügung gestellt.

Tabelle 2: Demografie der Teilnehmenden - Pilotstudie

	Personen mit MS (n=43)
Geschlecht (weiblich)	35 (81.4)
Alter (<i>M, SD</i>)	49.5 (9.29)
Bildung	
Haupt- / Realschulabschluss	12 (27.9)
Abitur	31 (72.1)
Familienstand	
Alleinstehend	7 (16.3)
Verheiratet / in einer partnerschaftlichen Beziehung	30 (69.8)
Geschieden	4 (9.3)
Verwidwet	1 (2.3)
Keine Angabe	1 (2.0)
Beschäftigung	
Berufstätig in Vollzeit	11 (25.6)
Berufstätig in Teilzeit	17 (39.5)
In Ausbildung	2 (4.7)
Arbeitslos	2 (4.7)
Krankheitsbedingt in Rente	10 (23.3)
In Altersrente	1 (2.3)

MS Verlaufstyp	
Schubförmige MS	24 (55.8)
Sekundär progrediente MS	6 (14.0)
Primär progrediente MS	6 (14.0)
Unbekannt	7 (16.3)
Jahre seit der Diagnose (M, SD)	13.2 (8.86)
PDDS (M, SD)	2.2 (1.47)
Haben Sie in den letzten drei Monaten einen Schub erlitten?	
Ja	2 (4.7)
Nein	41 (95.3)

Daten als Häufigkeiten, Prozentangaben in Klammern, wenn nicht anders angegeben. Mittelwert (M), Standardabweichung (SD).

Tabelle 3: GLTEQ Health Contribution Score und Nigg Physical Activity Staging Questionnaire prä/post

	GLTEQ Health Contribution Score (n=36)		
	unzureichend aktiv	mäßig aktiv	aktiv
Prä	17	8	11
Post	11	7	18
	Nigg Physical Activity Staging Questionnaire (n=35)		
	nicht regelmäßig aktiv	derzeit regelmäßig aktiv	langfristig regelmäßig aktiv
Prä	23	6	6
Post	14	9	12

Godin Leisure Time Exercise Questionnaire (GLTEQ)

3. Zusammenfassung

3.1 Zusammenfassung der Ergebnisse in deutscher Sprache

Acht Personen mit MS und vier MS Expert:innen nahmen an der Machbarkeitstestung teil und befassten sich mit den Fragebögen sowie der Programmwebseite. Die Teilnehmenden waren zufrieden mit den Inhalten des Programms und vergaben dem Programm durchschnittlich die Schulnote „gut“. Sie empfanden den Programminhalt motivierend und relevant für Personen mit MS, sodass alle Teilnehmenden der Machbarkeitstestung das Programm für Personen mit MS empfehlen würden. Im Rahmen der Pilotstudie begannen 43 Teilnehmende mit dem Programm, vier (9 %) brachen es vorzeitig ab und 36 (84 %) nahmen an der Umfrage nach der Intervention teil. Die Teilnehmenden waren überwiegend weiblich (81 %) und hatten ein Durchschnittsalter von 49,5 Jahren (SD 9,29). 31 von 43 (72 %) hatten einen Hochschulabschluss. Mehr als die Hälfte (56 %) gaben an, an schubförmiger MS erkrankt zu sein. Der mittlere PDDS betrug 2,2 (SD 1,47). Durchschnittlich wurden 9,8 Module bearbeitet. Der zeitliche Aufwand wurde als moderat eingeschätzt und die Teilnehmer benötigten durchschnittlich 13 Wochen für das Programm. Die mit dem GLTEQ Gesamtwert gemessene körperliche Aktivität nahm durch die Intervention von einem mittleren Wert von 26,19 (SD 23,40) bei Studienbeginn auf einen Wert von 34,97 (SD 20,24) bei der Nachuntersuchung (p-Wert 0,042) signifikant zu. Die Effektstärke (Cohen's d) beträgt 0,35. Verbesserungen bei der mittleren bis hohen körperlichen Aktivität, gemessen mit dem GLTEQ Health Contribution Score, waren ebenfalls nachweisbar: Während die Zahl der unzureichend und mäßig aktiven Teilnehmer:innen jeweils abnahm, stieg die Zahl der als aktiv eingestuften Teilnehmer:innen um sieben Personen. Ebenso steigerten mehr Teilnehmende ihre regelmäßige körperliche Aktivität, die mit dem Nigg Physical Activity Staging Questionnaire gemessen wurde und wechselten in die aktive beziehungsweise langfristig aktive Phase der Veränderung.

3.2 Zusammenfassung der Ergebnisse in englischer Sprache

Eight persons with MS and four MS exercise experts took part in the feasibility testing and completed the feasibility questionnaires. The participants were satisfied with the content of the program and rated the program with an average schoolgrade of two ("good"). They assessed the program content motivating and relevant and all participants in the feasibility testing would recommend the program for persons with MS. In the pilot study, 43 participants started the program, four (9%) dropped out early and 36 (84%) took part in the post-intervention survey. The participants were predominantly female (81%) and had an average age of 49.5 years (SD 9.29). 31 out of 43 (72%) had a high school degree. More than half of the participants (56%) reported having relapsing-remitting MS, with a mean PDDS of 2.2 (SD 1.47). On average, 9.8 modules were completed. The required time for the modules was rated as moderate and participants needed an average of 13 weeks to complete the program. Physical activity as measured with GLTEQ increased significantly with a mean GLTEQ Total Score of 26.19 (SD 23.40) at baseline to 34.97 (SD 20.24) at follow-up (p-value 0.042). The effect size (Cohen's d) was 0.35. Improvements in moderate to high physical activity, as measured with the GLTEQ Health Contribution Score, were also detectable: while the number of insufficiently and moderately active participants decreased, the number of participants classified as active increased by seven. Similarly, more participants increased their regular physical activity, as measured with Nigg Physical Activity Staging Questionnaire, and moved into the active or long-term active stage of change.

4. Erklärung des Eigenanteils

Activity Matters ist ein zwölfwöchiges, web-basiertes Programm zur Steigerung der körperlichen Aktivität bei Multipler Sklerose. Das von Susan Coote und Bláthín Casey in Irland entwickelte, verhaltenswissenschaftlich fundierte Selbstmanagementprogramm wurde professionell ins Deutsche übersetzt und durch Dr. Karin Riemann-Lorenz und Prof. Dr. Christoph Heesen an deutsche Verhältnisse und lokale Gegebenheiten in Hamburg angepasst. Um es Menschen mit MS zur Verfügung zu stellen, wurde eine Programmwebseite (www.activitymatters.de) von der Firma Take Part Media erstellt, auf der sich die Studienteilnehmenden durch elf strukturierte Module navigieren. Die Module basieren auf unterschiedlichen Indikatoren zur Verhaltenänderung mit dem Ziel, die körperliche Aktivität langfristig zu steigern.

Für die Machbarkeitstestung des übersetzten und adaptierten Programms wurden acht Patient:innen aus der MS Tagesklinik des Universitätsklinikums Hamburg-Eppendorf sowie über die DMSG Hamburg rekrutiert. Zusätzlich wurden vier MS- und Sport-Expert:innen aus Forschungsgruppen in Deutschland und den DMSG Landesverbänden rekrutiert. Die Rekrutierung und das Erstellen der Fragebögen für die Machbarkeitstestung übernahm Dr. Karin Riemann-Lorenz. Die Teilnehmenden der Machbarkeitstestung evaluierten das Programm für einen Zeitraum von vier Wochen und teilten im Anschluss ihre Eindrücke in den Fragebögen und halbstrukturierten Telefoninterviews. Die Interviews wurden von Dr. Karin Riemann-Lorenz und Nina Daniel durchgeführt und neben den Fragebögen gemeinsam ausgewertet. Die beiden Mitglieder des Studienteams nahmen vor der Pilotphase Änderungen an den Programminhalten vor, die sich durch die Machbarkeitstestung ergaben.

Anschließend erstellten Dr. Karin Riemann-Lorenz und Nina Daniel die Studieninformationen und E-Mail Vorlagen für die Teilnehmenden, um sie während der Pilotstudie einheitlich durch das Programm zu begleiten. Die Teilnehmenden der Pilotstudie wurden vor, während und nach der Teilnahme an *Activity Matters* dazu aufgefordert, Fragebögen zur Prozessevaluation auszufüllen. Die Fragebögen wurden von Nina Daniel erstellt, die ebenfalls die Rekrutierung der Pilot-Teilnehmer:innen in der MS Tagesklinik des Universitätsklinikums Hamburg-Eppendorf und innerhalb ehemaliger Studienteilnehmer:innen einer anderen Sportstudie durchführte. Um Interessierte von außerhalb auf die Studie aufmerksam zu machen, setzte sich Nina Daniel außerdem mit Personen in Kontakt, die sich in den sozialen Medien mit der Multiplen Sklerose beschäftigen. Die Teilnehmenden wurden dann in der Pilotphase I von Nina Daniel in das Programm eingeführt und während der Teilnahme per E-Mail oder telefonisch von ihr betreut. Die Abschlussinterviews wurden von Nina Daniel und Iris Bruns durchgeführt und ausgewertet. Nina Daniel und Dr. Karin Riemann-Lorenz werteten anschließend die Fragebögen zur Pilotstudie aus. Bei der Auswertung der Ergebnisse der körperlichen Aktivität unterstützte Anne Daubmann. Auf Basis der Ergebnisse der Pilotbefragungen erstellte Nina Daniel in enger Zusammenarbeit mit Dr. Karin Riemann-Lorenz das Manuskript und erhielt kontinuierliches Feedback von allen Ko-Autor:innen.

5. Danksagung

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6. Eidesstattliche Versicherung

Ich versichere ausdrücklich, dass ich die Arbeit selbständig und ohne fremde Hilfe verfasst, andere als die von mir angegebenen Quellen und Hilfsmittel nicht benutzt und die aus den benutzten Werken wörtlich oder inhaltlich entnommenen Stellen einzeln nach Ausgabe (Auflage und Jahr des Erscheinens), Band und Seite des benutzten Werkes kenntlich gemacht habe.

Ferner versichere ich, dass ich die Dissertation bisher nicht einem Fachvertreter an einer anderen Hochschule zur Überprüfung vorgelegt oder mich anderweitig um Zulassung zur Promotion beworben habe.

Ich erkläre mich einverstanden, dass meine Dissertation vom Dekanat der Medizinischen Fakultät mit einer gängigen Software zur Erkennung von Plagiaten überprüft werden kann.

Unterschrift: 