

PRELIMINARY DATA FROM A FEASIBILITY TRIAL OF AN ONLINE RESILIENCE INTERVENTION FOR PEOPLE WITH MULTIPLE SCLEROSIS: READY FOR MS

Lina Duemmer¹, Kenneth Pakenham², & Jana Poettgen¹

¹*Clinical and Rehabilitative MS Research, Institute of Neuroimmunology and Multiple Sclerosis,
University Medical Center, Hamburg (Germany)*

²*School of Psychology, The University of Queensland (Australia)*

Abstract

Multiple sclerosis (MS) is a chronic disease of the central nervous system, leading to significant physical burden and psychological challenges. The unpredictable nature of MS, characterized by relapses and progressive disability, further exacerbates psychological distress and negatively impacts quality of life. Although many people with MS (PwMS) experience significant psychological distress, there is a lack of psychotherapeutic options. In addition, only few interventions target resilience. As resilience, the ability to “bounce back” from adversity, is a key factor in coping with chronic diseases like MS, we developed and feasibility-tested an adapted German online version of the group-based resilience-enhancing program READY for MS. The program consists of a 7-module program with an additional booster session, which included videos, exercises, a personal plan and a workbook. In a single-arm feasibility study with n=19 PwMS (mean age 39.01 years; sex: 79% female) we collected data to assess program usability, perceived personal experiences and benefits, impressions and suggestions for improvement using a post-intervention survey. With a structured qualitative interview in a subset of n=5 participants we collected additional data on program satisfaction, usability and applicability. Interviews were transcribed and analyzed using qualitative content analysis, and survey data were subjected to descriptive analyses. Exploratory quantitative data on resilience, health-related quality of life, and psychological flexibility were also collected by an online survey pre- and post-intervention. Statistical analyses (Shapiro-Wilk test) were run by IBM SPSS (version 30.0). The program was well accepted, and both qualitative and quantitative findings indicated high satisfaction and perceived benefit. Participants reported greater self-reflection, awareness, and stress-resistance, and suggested minor structural and technological improvements. Quantitative results (n=19) indicated positive effects of the program on resilience (CD-RISC $p < .05$), quality of life (HAQUAMS $p < .05$), and psychological flexibility (MPFI flexibility $p < .05$; inflexibility $p < .05$). The German online version of READY for MS appears to be a feasible and well-accepted intervention to support resilience in PwMS. Preliminary data indicate significant beneficial effects on psychological flexibility and inflexibility. The next step is a randomized controlled trial to study the effectiveness of READY for MS (started in January 2026).

Keywords: *Multiple sclerosis, resilience, quality of life, mental health, acceptance and commitment therapy (ACT).*

1. Introduction

Multiple sclerosis (MS) is one of most common autoimmune inflammatory diseases of the central nervous system. It is a complex degenerative illness characterized by inflammation, demyelination and neurodegeneration in the brain and the spinal cord. The course of MS is unpredictable, and symptoms vary widely and can adversely affect most areas of a person's life, often producing fluctuating and debilitating levels of disability (Compston & Coles, 2008). Consequently, PwMS are more likely to report lower quality of life (QoL) and clinically significant psychological distress than people in the general population (Drathen et al., 2024). In particular, prevalence rates of depression (30.5%) and anxiety (22.1%) are high (Boeschoten et al., 2017). Resilience in the face of such challenges is essential for optimizing adjustment to the fluctuating demands of the illness over the long haul. Resilience involves negotiating, managing, and adapting to significant stressors or trauma by activating both internal (e.g., mindfulness, acceptance, cognitive flexibility, and active coping) and external (e.g., social support, financial capital, and community

services) resources (Windle et al., 2011). Resilience has been linked to better psychosocial and mental health outcomes and motor functioning in PwMS (Klineova et al., 2020; Koelmel et al., 2017; Silverman et al., 2017). Resilience has also been shown to ameliorate the adverse effects of fatigue and pain on QoL in PwMS (Terrill et al., 2016). Although resilience appears to be an important protective factor in coping with the challenges of MS, PwMS report lower levels of resilience than community samples and people with other chronic illnesses (Terrill et al., 2016). Hence, developing interventions that promote resilience in PwMS is a priority research endeavor.

Three published resilience training interventions for PwMS have been developed. These interventions have been informed by positive psychology (Alschuler et al., 2018), a purpose-built resilience framework (Halstead et al., 2020), and acceptance and commitment therapy (ACT) (Pakenham et al., 2018). Preliminary evaluations of their efficacy suggest they are effective in cultivating resilience and/or associated protective factors (e.g., social support). The ACT intervention called READY for MS (Pakenham et al., 2018) is the most widely researched and rigorously tested resilience intervention for PwMS and is the focus of this study. READY for MS was derived from a group resilience training program called “RESili-ence Activities for every DaY” (READY) that was effectively applied to people with cancer (Hawkes et al., 2013), congenital heart disease Steele (2016), and diabetes (Ryan et al., 2020) and staff in a workplace setting (Burton et al., 2010). A modified version of the program for PwMS was developed and called READY for MS (Pakenham et al., 2018).

READY for MS is based on ACT (Hayes et al., 2016), a contemporary variant of cognitive behaviour therapy. Reviews suggest that ACT interventions show promise in promoting mental health and QoL in PwMS (Thompson et al., 2022). ACT is underpinned by the psychological flexibility framework. ACT promotes psychological flexibility, which involves behaving consistently with one’s chosen values even in the presence of unwanted intrusive internal experiences such as emotional discomfort or self-critical thinking (Hayes et al., 2016). Evaluations of READY for MS have supported its theoretical foundation by demonstrating that therapeutic change occurs through psychological flexibility, the mechanism of action proposed by the ACT framework (Hayes et al., 2016). READY for MS has been successfully applied in numerous cultural contexts including Australia, Italy, United Kingdom, Greece and Israel. It has also been delivered in various modes including in-person group (Giovannetti et al., 2020; Giovannetti et al., 2022; Pakenham et al., 2018), group via real time videoconferencing (Theodorou et al., 2022), and online self-directed format (Pakenham & Landi, 2023) Wicks et al., 2023). The self-directed online version is referred to as e-READY for MS. The purpose of the present study was to develop a German version of the digital READY for MS and evaluate it in a feasibility single arm pilot mixed methods study.

2. Methods

The study design is a single intervention condition with pre- and post-intervention assessments. Qualitative data was collected at post-intervention via semi structured interviews with a sub-sample of participants. Quantitative data was collected via an online survey for demographics and MS clinical details at pre-intervention, resilience and QoL at pre- and post-intervention and online program usability at post-intervention.

PwMS were recruited from the MS outpatient clinic of UMC Hamburg-Eppendorf. Inclusion criteria were MS diagnosis, >17 years old, and German language skills. The study was approved by the Ethics Committee of the Hamburg Chamber of Psychotherapists (01/2024).

2.1. Intervention

The e-READY for MS program consists of seven weekly modules plus a booster module five weeks after the seventh module. The seven module topics and order of presentation are as follows: 1) Introduction to the READY Resilience Model, 2) Mindfulness, 3) Acceptance, 4) Defusion I, 5) Defusion II and Self-as-context, 6) Values and Meaningful Action, 7) Review and Future Planning. The booster module provides a review of program information. Program strategies include psychoeducation, experiential exercises, guided meditations, metaphors, self-reflection tasks, self-monitoring, in-session practice activities, and home practice assignments. Participants receive a workbook that has two components: 1) module content and 2) the READY Personal Plan which is comprised of in-session and home practice exercises. Participants record their personal practice in the Personal Plan. The Personal Plan constitutes a personalized resource to help participants apply program strategies to their specific context. The workbook was provided as a PDF file; however, a hard copy of the Personal Plan was also sent to participants. Participants received an audio recording of meditations. The entire online program is guided by two animated characters whose voiceovers were recorded by professional actors. The digital READY for MS modules were integrated into the UKE@home platform, a secure website developed for research purposes and hosted by the University Medical Center Hamburg-Eppendorf.

2.2. Semi-structured interviews

Semi-structured interviews were conducted by LD with five participants. Interviews inquired about overall impressions of the program, as well as views on its challenges, usability, perceived benefits and effects on resilience and psychological well-being, and suggestions for improvement. The semi-structured interview guideline was based on Helfferich's (2009) approach to ensure consistency across all interviews.

2.3. Quantitative measures

The online survey (Lime survey hosted by the University of Hamburg) collected data on demographics (age, gender, education, employment) and MS (disease duration, MS disease course, perceived disability level (Patient Determined Disease Steps Scale (Learmonth et al., 2013)). The survey also included validated standardised multi-item scales used in prior MS research that measured resilience (Connor-Davidson-Resilience-Scale 25 (CD-RISC-25), (Connor & Davidson, 2003)), QoL (Hamburg Quality of Life Questionnaire in Multiple Sclerosis (HAQUAMS (Gold et al., 2001))), psychological flexibility (Multidimensional Psychological Flexibility Inventory (MPFI (Rolffs et al., 2018))) and online program usability (System Usability Scale (SUS), (Lewis, 2018)).

2.4. Data analysis approach

Interviews were recorded and transcribed. Transcriptions of interviews were subjected to qualitative software (MAXQDA24 (1989 – 2025, VERBI Software. Consult. Sozialforschung GmbH, Berlin, Germany) which identified categories through a structured coding process (guidelines by (Kuckartz & Rädiker, 2019)). Regarding quantitative analyses (IBM SPSS Statistics Version 30.0.0.0), Shapiro-Wilk paired-samples t-tests and Wilcoxon signed-rank one-sided tests were used to examine changes from pre-intervention to post-intervention in measures of resilience, QoL and psychological flexibility. We used a significance level of $\alpha = 0.05$.

3. Results

3.1. Qualitative

Four key themes emerged from the qualitative analyses. The first theme was labelled 'perceived effects on everyday life' and subsumed four sub-themes that reflected the positive effects of the e-READY for MS program on daily living including increased reflection and emotional awareness, greater awareness of stress and MS symptoms, and resilience. The second theme 'program use and engagement' had four sub-themes that reflected variability in engagement with program resources, time demands of the program, importance of program completion and program user friendliness. The third theme 'perceptions of program content' was composed of sub-themes that identified positive aspects of the program including an overall positive impressions, particularly helpful modules (e.g., mindfulness and acceptance) and useful resources (e.g., personal plan), as well as identifying challenging modules such as the defusion module. Finally, the fourth theme was labeled 'recommendations and improvement suggestions'.

3.2. Quantitative

A total of 19 PwMS participated in the quantitative study. The mean age of participants was 39.01 years and most (79%) were female. Just over half (53%) had a university degree and most (61%) were employed. The mean MS illness duration was 8.68 years. All but two participants reported a relapse remitting course of MS. Regarding engagement in the program, all participants completed module 1 (Introduction) and module 3 (Acceptance). Completion rates for the remaining modules ranged from 89% ($n = 17$) to 79% ($n = 15$).

Explorative statistical analyses showed that psychological flexibility (MPFI mean change +0.98, $p < .05$), psychological inflexibility (MPFI mean change -.71, $p < .05$), resilience (CD-RISC mean change +3.5, $p < .05$), and two QoL dimensions (HAQUAMS mood (mean change -.35, $p < .05$) and social function (mean change -.11, $p < .05$)) significantly improved from pre- to post-intervention.

Results from the online program usability questionnaire (SUS) showed all 19 participants indicated that they would recommend the program to other PwMS. Furthermore, some suggested that the program could be helpful for people with other health conditions. Several minor program improvements were suggested which primarily concerned technology upgrades. The questionnaire also included items assessing how participants used the program. The results indicated high retention, with 15 participants completing all eight modules of the online program. Twelve participants reported engaging with the READY for MS content quite extensively or very extensively. In contrast, engagement with the Personal Plan decreased over the course of the program. While 17 participants completed the exercises associated with Module 1,

only five participants completed all exercises in Module 8. Nevertheless, most participants reported using the Personal Plan to some degree.

4. Discussion

This study evaluated the acceptance and feasibility of the German online version of e-READY for MS, an ACT-based resilience program, in a small sample of PwMS ($n = 19$) using a mixed-methods approach with a focus on qualitative data. Qualitative analyses showed that participants reported high satisfaction with the program and described positive intervention effects on daily life and coping with MS. They also provided suggestions for further program improvement.

Exploratory quantitative analyses indicated trends toward improvements in resilience, quality of life, and psychological flexibility from pre- to post-intervention. The qualitative and quantitative data convergence on the positive effects of the German e-READY for MS on a range of psychosocial outcomes. Findings are consistent with previous evaluations of READY for MS delivered in different languages and formats, where participants also reported increased mindfulness, better stress management, improved QoL and new coping strategies.

Limitations include the small sample size and the high educational level of participants, which may limit the generalizability of findings. Some participants also noted technical usability issues.

5. Conclusions

This study represents an important first step toward establishing an evidence-based, fully digital intervention to strengthen resilience in PwMS in Germany. Findings provide valuable insights to guide further program development and evaluation. Results warrant testing the efficacy of the German e-READY for MS in a full scale randomized controlled trial.

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