Evaluation of a Brief Mindfulness Program for People with Multiple Sclerosis Delivered in the Community Over Five Years

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Abstract

This study evaluated the effectiveness, change mechanisms, and sustainability of a brief mindfulness intervention for people with multiple sclerosis (PwMS) delivered in the community through a frontline service over five years. Participants were 126 PwMS. A single intervention condition design was used with pre-intervention, post-intervention and 2-month follow-up assessments. The primary outcome was distress. Secondary outcomes were perceived stress, quality of life (QoL) and fatigue, and the proposed change mechanisms: mindfulness, self-compassion, psychological inflexibility. Intention-to-treat analyses showed the primary outcome, distress (Cohen's $d = .25$), and all secondary outcomes improved: perceived stress ($d = .38$), mental health QoL ($d = .39$), physical health QoL ($d = .47$), fatigue ($d = .30$), mindfulness ($d = .29$), self-compassion ($d = .37$), psychological flexibility ($d = .44$). Distress, stress and perceived stress continued to improve post-intervention to follow-up. Mindfulness emerged as a temporal mediator of perceived stress (BCa 95% CI). Self-compassion mediated concurrent improvements in distress, perceived stress, fatigue and physical health QoL, while greater psychological flexibility mediated concurrent reductions in distress (BCa 95% CI). Mindfulness home practice was unrelated to improvements on all outcomes except a marginal association with mindfulness. Of the socio-demographic and illness factors, lower disease severity predicted improvements in physical health QoL ($p = .046$). Improvements in outcomes were supported by qualitative feedback and participant satisfaction ratings. Twenty-one groups were offered with good participant engagement and wide geographical reach, suggesting sustained feasibility of the Mindfulness for MS program over five years. Findings support the delivery of the Mindfulness for MS program through a community-based service in partnership with a local university.

Keywords Acceptance · Mindfulness · Quality of life · Self-compassion · Stress · Distress

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Note. The term "**blinded**" is used to replace information that could identify the authors such as names of institutions and geographical locations. The term "**author**" is used to refer to articles written by the authors which could identify them.

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Introduction

Multiple sclerosis (MS) is an inflammatory, progressive demyelinating disease of the central nervous system. With a lifetime risk of 1 in 400, it is the most common cause of progressive neurological disability in young adults (Compston & Coles, 2002). It is estimated that globally 2.3 million people are affected by MS (Browne et al., 2014). The onset of MS is most often in young adulthood (Multiple Sclerosis International Federation, 2013), the aetiology is unknown, and there is currently no cure, only symptomatic relief (Noseworthy et al., 2000; Thomas et al., 2006). The course of MS is unpredictable and clinical symptoms vary in nature and severity over time, and between individuals (Zaffaroni & Ghezzi, 2000). Fatigue is one of the most common symptoms of MS and significantly impacts daily functioning (Compston & Coles, 2002). MS produces profound psychosocial disruptions in areas such as employment, sexual functioning, family life and activities of daily living. People with MS (PwMS) experience lower quality of life (QoL) (McCabe & McKern, 2002) and are more likely to report clinically significant psychological distress than people in the general population (Boeschoten et al., 2017). In particular, prevalence rates of depression (30.5%) and anxiety (22.1%) are high (Boeschoten et al., 2017). In addition, evidence suggests the occurrence of stressful life events leads to a greater risk for MS relapses (Mohr et al., 2004). QoL, distress and stress are therefore, important targets for psychological interventions.

Psychological factors account for greater variability in psychosocial functioning than MS disease factors (Dennison et al., 2009). An important protective psychological factor is mindfulness, which is associated with greater QoL, resilience and adjustment, and less fatigue in people with MS (e.g., Pakenham & Samios, 2013; Senders et al., 2014; Tavee et al., 2011). A review of mindfulness-based interventions (MBIs) for PwMS found few published studies. However, there was preliminary evidence to support the beneficial effects of MBIs on mental health, QoL and physical functioning (Simpson et al., 2014). Subsequently, additional MBI studies in MS have been published. Most have been delivered in groups (Carletto et al., 2017; Grossman et al., 2010; Senders et al., 2018; Tavee et al., 2011) with one delivered individually (Mills & Allen, 2000), and more recently delivery via telecommunication (Bogosian et al., 2015; Cavalera et al., 2019; Frontario et al., 2016).

Most published MBIs for PwMS have involved lengthy group programs (Bogosian et al., 2015; Gilbertson & Klatt, 2017; Grossman et al., 2010; Hoogerwerf et al., 2017; Mills & Allen, 2000; Tavee et al., 2011). The duration of most MBIs for PwMS is around eight weeks, which is based on the most widely researched MBI, Mindfulness Based Stress Reduction (MBSR) (8-week, 26-h program; Kabat-Zinn, 1990) and it's variation, Mindfulness Based Cognitive Therapy (MBCT) (2.5 h 8-weekly sessions; Teasdale et al., 2000). For PwMS, factors such as fatigue, pain and reduced mobility can be barriers to attending lengthy MBIs (Simpson et al., 2015). Baer et al. (2012) examined weekly changes during an MBSR program and found that significant increases in mindfulness and reductions in perceived stress occur in as few as 2–4 weekly sessions. In addition, most MBIs for PwMS have been delivered in hospital settings. MBIs delivered in the community are likely to be more accessible, comfortable and cost-effective. For example, Simpson et al. (2019) investigated the views of PwMS completing an exploratory 2-phase MBSR program. Qualitative data indicated

that participants recommended that the accessibility of the program for PwMS could be increased by delivering the course in a disability-friendly environment in terms of transport, location (e.g. ground-floor room) and toilets.

Addressing both the brevity and community delivery of MBIs, a pilot study evaluated a brief, community-based group mindfulness intervention for PwMS called Mindfulness for MS (Spitzer & Pakenham, 2018). The program consists of five weekly two hour group mindfulness training sessions delivered in the community. Participants in the pilot showed improvements in perceived stress, distress, mental health QoL, mindfulness, self-compassion and acceptance.

Dissemination and uptake of evidence-based practice in clinical settings is essential to ensure optimal care of people with physical and mental health problems. However, there remains a significant disconnection between research validated psychosocial interventions and those routinely offered by community organisations (Rogers, 2003). Furthermore, empirically supported psychological interventions are seldom integrated into frontline services in ways that ensure long term delivery (McHugh & Barlow, 2010). One way to optimize the uptake and sustained delivery of such interventions is through collaborative partnerships between the researchers who develop and evaluate them and frontline services. The purpose of the present study was to further evaluate the effectiveness, sustainability and feasibility of the Mindfulness for MS program delivered through a community-based organisation over a five year period in collaboration with the program developers.

MBI Change Mechanisms

Understanding the mechanisms of change in MBIs in PwMS is important in order to optimise interventions for this population. However, only one published MBI study in MS has examined change mechanisms. This study found a dimension of mindfulness (decentring), acceptance, self-compassion and self-efficacy mediated the beneficial effects of mindfulness on distress (Bogosian et al., 2016). A meta-analysis investigated MBI change mechanisms across 20 studies and amongst the mediators identified were mindfulness, self-compassion and psychological flexibility (Gu et al., 2015). The role of these three proposed MBI change mechanisms will be examined in the present study.

Mindfulness Participation in MBIs is associated with increased mindfulness, which in turn, is associated with positive changes in psychosocial outcomes (Khoury et al., 2013, 2015). Bogosian et al. (2016) showed that mindfulness decentring skills mediated the beneficial effects of an MBI on distress in PwMS. Decentring is related to metacognitive insight and refers to the process of observing thoughts and emotions.

Self-Compassion Self-compassion has three components: mindfulness (vs. over-identification), self-kindness (vs. self-judgement) and common humanity (vs. isolation) (Neff, 2003). A meta-analysis by MacBeth and Gumley (2012) found a robust relationship between higher self-compassion and lower psychopathology. Evidence suggests that participation in MBIs increases self-compassion (Birnie et al., 2010; Robins et al., 2012). Self-compassion has been shown to mediate improvements in distress in PwMS who participated in an MBI (Bogosian et al., 2016).

Psychological Flexibility Acceptance and Commitment Therapy (ACT) defines psychological flexibility as paying attention to the present moment, without defence, while consciously choosing to take action consistent with personal values even in the presence of discomfort (Hayes et al., 1999). The ACT psychological flexibility framework includes six core processes, one of which is mindfulness. Psychological flexibility has been shown to mediate the intervention effects of an MBI for nurses (Duarte & Pinto-Gouveia, 2017), and of a public health ACT and mindfulness training intervention delivered in the community (Fledderus et al., 2010).

The Present Study

The first aim of this study was to evaluate the effectiveness of the delivery of the brief community-based intervention, Mindfulness for MS, over a five-year period. We hypothesised that participants would evidence significant improvements on the primary outcome distress, and on the secondary outcomes perceived stress, fatigue and QoL, and the proposed change mechanisms: self-compassion, psychological flexibility and mindfulness.

The second aim was to investigate whether self-compassion, psychological flexibility and mindfulness mediated the beneficial impacts of mindfulness training on distress, stress, fatigue and QoL. We hypothesised that increases in mindfulness, psychological flexibility and self-compassion would mediate improvements on these outcomes.

Method

Research Design

We used a single intervention condition design, with assessments at pre-intervention, post-intervention and 2-month follow-up. Qualitative and quantitative data were collected via online questionnaires (and hard copy where required). Ethical clearance was obtained through the University of Queensland (#2015001499).

Participants, Recruitment and Procedure

Eligible participants were adults (over 18 years) with a self-reported diagnosis of MS and who were fluent in English and could travel to community locations to attend the program. Participants were recruited through the Multiple Sclerosis Society of Queensland (MSQ) in Australia via flyers posted on the MSQ social media page and emailed to MSQ members. Flyers provided information on program dates, location, facilitator's name and qualification, purpose of the program, MSQ contact details and a definition of mindfulness.

MSQ staff received expressions of interest and screened participants for suitability. Exclusion criteria included severe physical or cognitive impairment that was likely to interfere with engagement in the program. MSQ offered such individuals alternative support options. MSQ obtained consent for participant contact details to be sent to the facilitator of each program. Facilitators contacted participants via telephone and

introduced the research program evaluation procedure. Individuals interested in participating in the research were emailed an information sheet and consent form along with a link to the first online questionnaire. Included in each email was a unique participant identification code for use when completing all questionnaires, so that responses remained anonymous.

Mindfulness for MS Program

The Mindfulness for MS program consists of 5×2-h weekly group sessions. The program was adapted from MBSR (Kabat-Zinn, 1990) and MBCT protocols (Teasdale et al., 2000). These protocols were adapted so that participation was not limited by common MS symptoms. For example, mindful movement exercises were excluded to accommodate mobility limitations, regular breaks were scheduled to account for MS fatigue, and the introduction of the body scan exercise was delayed (until session two) due to commonly experienced painful physical sensations. No alterations were made to the piloted Mindfulness for MS protocol in the present study given that only six of the 23 pilot study participants suggested minor changes and that each recommended modification was mentioned by only one or two participants.

Each session includes both formal mindfulness meditation and informal mindfulness exercises. The latter were used to encourage the integration of mindful awareness into everyday activities. Exercises were followed by a debriefing and discussion of how mindfulness might enhance effective coping with MS. Refer to the pilot study for details of the program content (Spitzer & Pakenham, 2018).

Participants were encouraged to practice both formal and informal mindfulness practices for a total of 30 min per day. Participants were asked to record their weekly practice on a monitoring form and return it to the facilitator each week. To assist with home practice, each participant was provided with a CD that contained the weekly guided formal mindfulness meditations. At the end of each session participants were given a handout that summarised the session content. If a participant did not attend a session, the facilitator contacted the participant via telephone to provide a brief overview of the session content and home practice. Participants were sent generic weekly reminder emails encouraging daily practice between sessions. A carer could attend sessions where carer support was relevant for a participant's engagement in the program.

A facilitator's manual was used to guide the delivery of the program content. Facilitators were either registered psychologists working in the community or provisionally registered psychologists who were students enrolled in the postgraduate clinical psychology degree at the University of Queensland. Although intervention fidelity was not directly assessed, all facilitators received training and supervision from one of the program authors. All student facilitators had received training in mindfulness interventions through their postgraduate clinical psychology degree. In addition, they received an introductory in-person one hour training session and weekly supervision for the duration of their first delivery of the Mindfulness for MS program. The qualified psychologists working in the community who delivered the program had clinical experience in delivering mindfulness interventions and received a phone delivered

introduction to the intervention by one of the program authors and phone supervision on a needs basis.

Measures

Measures of participant illness status and socio-demographics were administered at pre-intervention. Primary and secondary outcome measures were administered at all three assessments. Participant intervention feedback was collected at post-intervention. The internal reliability data for all primary and secondary outcomes at each assessment point are displayed in Table 1.

Primary Outcome Measure *Distress*. The 21-item Depression, Anxiety and Stress Scale measured depression, anxiety and stress and has well-established reliability and validity (Lovibond & Lovibond, 1995).

Secondary Outcome Measures *Fatigue.* The Modified Fatigue Impact Scale measured fatigue symptoms in the past week and has demonstrated satisfactory reliability and validity (Fisk et al., 1994). *Perceived Stress.* The Perceived Stress Scale (Cohen et al., 1983) has good reliability and has been validated with an MS population (Wu & Amtmann, 2013). *Quality of Life.* The Short Form Health Survey (SF-36) (Ware et al., 2000) assessed QoL in 8 domains: general health, physical functioning, pain, social functioning, role limitations due to physical health, role limitations due to emotional health, vitality, and mental health. Two summary scores are calculated: physical health and mental health. The 1-week recall measure was used due to its sensitivity to recent health changes (Ware et al., 2000). The SF-36 has well established reliability and validity and has been used with MS samples (e.g., Tavee et al., 2011).

Table 1 Cronbach Alpha's for outcomes at pre- and post-intervention and follow-up

Outcomes	Pre-intervention	Post-intervention	Follow-up
Primary Outcome			
Distress Total	.86	.81	.80
Depression	.90	.93	.94
Anxiety	.79	.72	.74
Stress	.90	.87	.89
Secondary Outcomes			
Perceived Stress	.90	.90	.89
Mental Health Quality of Life	.59	.73	.70
Physical Health Quality of Life	.72	.55	.66
Fatigue	.83	.87	.87
Proposed Change Mechanisms:			
Psychological Flexibility	.95	.96	.94
Self-compassion	.87	.89	.88
Mindfulness	.68	.79	.81

The proposed change mechanisms (mindfulness, self-compassion, psychological inflexibility) were measured as follows. *Self-compassion.* The widely used 26-item Self-Compassion Scale (Neff, 2003) has six dimensions: self-kindness, self-judgement, common humanity, isolation, mindfulness and over-identification. The scale has good reliability and validity (Neff, 2003). *Psychological Flexibility.* The 7-item Acceptance and Action Questionnaire-II (Bond et al., 2011) assessed psychological flexibility. Lower scores indicate higher psychological flexibility. The instrument has sound reliability and validity (Bond et al., 2011). *Mindfulness.* Mindfulness was measured by the Five Facet Mindfulness Questionnaire Short Form (Bohlmeijer et al., 2011), which assesses five dimensions: observing, describing, acting with awareness, non-judging of inner experience and non-reactivity to inner experience. The measure is sensitive to change and has good reliability and validity (Bohlmeijer et al., 2011).

Illness Status *MS Disease Severity.* Disease severity was assessed via a self-report version of the Physician's Disease Steps Scale (Hohol et al., 1995), which measures MS-related mobility limitation. Participants were classified into 3 broad categories: mild 40.5% ($n = 51$), moderate 43.6% ($n = 55$) and severe 14.3% ($n = 18$) (1.6% were missing, $n = 2$). *MS Disability.* Disability was assessed by the 13-item version of the Activities of Daily Living Self-Care Scale for PwMS (Gulick, 1987), which has been used in prior research (e.g., Pakenham, 2007). *Illness duration and type of MS.* Participants were asked to identify whether they had received an MS diagnosis from a physician ("yes" or "no"), the course of their MS (relapsing-remitting, primary-progressive or secondary progressive) and when they received their diagnosis (months, years).

Socio-Demographics *Meditation Experience.* Participants were first asked if they had any meditation experience ("yes" or "no"). Those who responded "yes" were asked to identify the type of meditation practice (mindfulness or other), length of time practicing meditation (months and years), and how frequently meditation was practiced (daily, several times a week, once a week, once a month, rarely or other). **Demographics.** Forced-choice questions obtained information on gender, employment status and level of education. Open-ended questions obtained information on date of birth, postcode, country of birth, and language mostly spoken at home.

Home Practice Records At the end of each session for weeks 1–4, participants were given a form for tracking home practice. Each home practice was recorded with respect to: date, type of practice (formal or informal), exercise (e.g., body scan), duration (minutes) and reflection (optional). Forms were collected at the start of the next group session.

Sustained Program Feasibility To assess program feasibility and sustainability, the number of programs offered, participant recruitment and retention, number and status of facilitators and geographical location of programs were documented. Participant engagement was gauged by the amount of time (minutes) in daily home mindfulness practice (see monitoring form described above).

Participant Satisfaction and Feedback. Participant satisfaction was assessed by ratings on a 5-point scale (1 = "strongly disagree" to 5 = "strongly agree") for the following statements: "Overall I found the program helpful", "I would recommend the program to others with MS", "Doing the program was enjoyable". Participants were also asked

open-ended questions about program components that were most helpful, personal changes since attending the program, how the program had impacted their thoughts, feelings and management of MS, and aspects of the program that should be changed.

Data Analysis Approach

For all analyses, IBM SPSS Statistics version 25 was used. Due to the exploratory nature of the study, the significance level $p < 0.05$ was used. Preliminary analyses compared post-intervention and follow-up questionnaire completers and non-completers on pre-intervention socio-demographics, illness status, and primary and secondary outcomes using one-way ANOVAs and chi squares.

Participants who completed all questionnaires (pre-intervention, post-intervention and follow-up) constituted a per-protocol (PP) sample ($n = 38$). The PP sample was based on adherence to completion of questionnaires, not to intervention protocol because of limited session attendance data. An intention-to-treat (ITT) sample was also created using multiple imputation in SPSS. Multiple imputation is a method used to analyse incomplete data sets and includes observed data and imputed data (predicted values based on observed data) (Rubin, 1996). All participants who completed the pre-intervention questionnaire ($n = 126$) were included in analyses.

Intervention related changes in primary and secondary outcomes were examined using repeated measures ANOVAs for both PP and ITT samples. Repeated measures contrasts with Bonferroni corrections were used following significant ANOVA results to compare intervention effects from pre- to post-intervention, and post-intervention to follow-up. Regarding effect size, partial eta squared was used for main effects and Cohen's d is reported for two-way follow-up comparisons using the formula, $d = (M_2 - M_1)/SD_{pooled}$. Effect sizes were interpreted as small (0.2), moderate (0.5) and large (0.8) (Cohen, 1992).

A series of mediational analyses were conducted on both the PP and ITT samples to examine whether changes on the proposed change mechanisms (psychological flexibility, self-compassion and mindfulness) mediated significant changes in the primary outcome and in perceived stress, fatigue and QoL from post-intervention to follow-up. Separate models were run for each significant change in these outcomes and both temporal and concurrent mediational models were examined. Mediational analyses were conducted using the SPSS macro MEMORE for repeated measures bootstrap analysis with multiple proposed mediators (Montoya et al., 2017). The total, direct and indirect effects of time (independent variable) on each outcome (dependent variable) through one or more mediators (the proposed change mechanisms) were estimated, and confidence intervals (CIs) were provided for the indirect effects using bootstrapping for 5000 samples. The percentile bootstrap method was used, due to increased reliability for smaller samples (Creedon & Hayes, 2015). Mediation is significant if the 95% percentile CI for the indirect effect does not include zero (Preacher & Hayes, 2004).

Multivariate ANCOVAs were conducted to explore whether socio-demographic and illness factors predicted post-intervention scores on all outcomes, controlling for pre-intervention outcome scores. Linear regressions were conducted to examine whether changes in post-intervention primary and secondary outcomes were related to the amount of home practice.

Finally, sustained program feasibility was examined using descriptive data for program offerings, recruitment, retention, engagement (based on home practice completion), facilitator numbers and status, geographical reach and participant satisfaction ratings. Responses to open-ended program feedback questions were analysed according to Braun and Clarke's (2006) steps for thematic analysis.
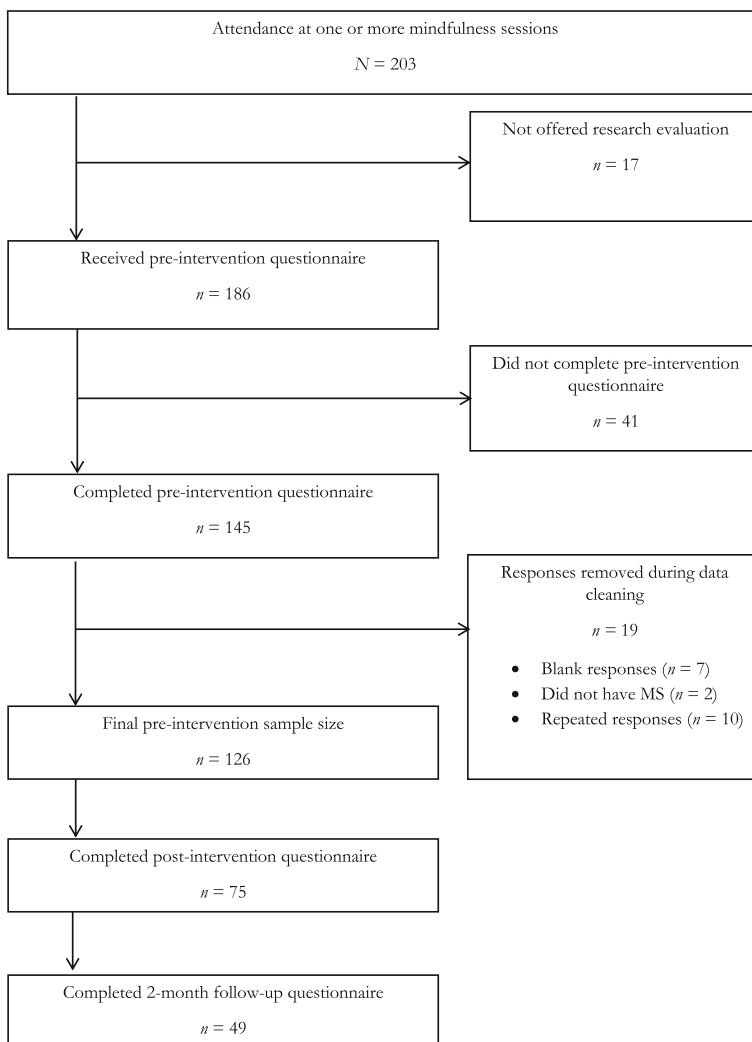
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┌────────────────────────────────────────────────┐
│     Attendance at one or more mindfulness sessions │
│                    N = 203                      │
└────────────────────────────────────────────────┘
                                    ┌──────────────────────────────┐
                                    │ Not offered research evaluation │
                                    │            n = 17            │
                                    └──────────────────────────────┘
┌────────────────────────────────────────────────┐
│     Received pre-intervention questionnaire     │
│                    n = 186                      │
└────────────────────────────────────────────────┘
                                    ┌──────────────────────────────┐
                                    │ Did not complete pre-intervention │
                                    │          questionnaire          │
                                    │            n = 41            │
                                    └──────────────────────────────┘
┌────────────────────────────────────────────────┐
│     Completed pre-intervention questionnaire    │
│                    n = 145                      │
└────────────────────────────────────────────────┘
                                    ┌──────────────────────────────┐
                                    │ Responses removed during data │
                                    │           cleaning           │
                                    │            n = 19            │
                                    │                              │
                                    │  • Blank responses (n = 7)   │
                                    │  • Did not have MS (n = 2)   │
                                    │  • Repeated responses (n = 10) │
                                    └──────────────────────────────┘
┌────────────────────────────────────────────────┐
│       Final pre-intervention sample size        │
│                    n = 126                      │
└────────────────────────────────────────────────┘
┌────────────────────────────────────────────────┐
│    Completed post-intervention questionnaire    │
│                    n = 75                       │
└────────────────────────────────────────────────┘
┌────────────────────────────────────────────────┐
│   Completed 2-month follow-up questionnaire     │
│                    n = 49                       │
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Fig. 1 Participant flow

Results

Participant Flow and Characteristics

Participant flow is summarised in Fig. 1. A total of 203 PwMS participated in one of the 21 mindfulness programs that were conducted. Of these, 186 participants were invited to participant in the research evaluation. Two mindfulness for MS groups consisting of 17 members and facilitated by community psychologists in regional areas were not offered participation in the research evaluation because of logistical difficulties in implementing the study protocols. A total of 145 participants completed the online pre-intervention questionnaire, and 126 of these were deemed valid during data screening. Seventy-five participants completed the post-intervention questionnaire, and 49 completed the follow-up assessment.

Table 2 summarises demographic characteristics of participants at pre-intervention ($n = 126$). Participants were mostly female and only two participants spoke languages other than English at home. The most frequently reported MS course was relapsing-remitting (70%) and the mean duration of MS was nine years.

Data Management and Preliminary Analyses

Data cleaning revealed errors in response entries including: missing participant identification codes ($n = 7$) and replication of participant identification code and/or participant characteristics (e.g., date of birth or postcode) across two questionnaires ($n = 10$). Data from two additional participants were removed because they answered 'no' to the question "Do you have a diagnosis of MS?"

Missing data was examined using Little's Missing Completely at Random test, which was not significant, χ^2 1431.67, $DF = 19,302$, $p = 1.000$, indicating that the data was missing completely at random. Loss of participant data was primarily due to attrition across assessment points, with 40.5% and 61% of participants not completing the post-intervention and follow-up questionnaires, respectively.

Multiple imputation was used to manage missing data and create an ITT sample. The ITT sample was formed using the primary outcome and all secondary outcomes. Expectation maximisation was applied to the 126 participants who completed the pre-intervention questionnaire. A total of 40 imputations were requested due to the high amount of missing data, and pooled results are reported (Graham et al., 2007).

Results of repeated measures ANOVAs and mediation analyses conducted on the PP sample were compared to those conducted on the ITT sample. The pattern of results for each sample were similar, hence, the results from the ITT sample are reported from here-on.

Analyses showed that post-intervention and follow-up assessment completers and non-completers did not differ on illness factors, socio-demographics, distress, perceived stress or the proposed change mechanisms but they differed on fatigue ($F(2,123) = 3.15$, $p = .046$), mental health QoL ($F(2,123)$ $p = .016$), and physical health QoL ($F(2,123)$ $p = .002$). Compared to completers, non-completers reported significantly higher fatigue ($p = .049$), and lower physical health QoL ($p = .017$) and mental health QoL ($p = .013$).

Table 2 Participant socio-demographics and illness status at pre-intervention (*N* = 126)

	N	%	
Sex			
Male	19	15.07	
Female	106	84.12	
Missing	1		
Country of birth			
Australia	87	69.04	
Not Australia	32	25.39	
Missing	7		
Language spoken at home			
English	124	98.41	
Other	2		
Education			
High school	28	22.22	
Trade	44	34.92	
University or above	53	51.58	
Missing	1		
Employment			
Unable to work	44	34.92	
Retired	32	25.39	
Part-time or Casual	23	18.25	
Full-time	21	16.66	
Unpaid	6	4.76	
MS type			
Relapsing-remitting	88	69.84	
Secondary-progressive	15	11.90	
Primary-progressive	20	15.87	
Missing	3		
Past meditation experience			
Yes	61	48.41	
No	64	50.79	
Missing	1		
If meditation experience, what type?			
Mindfulness Meditation	31	50.81	
Other	26	42.62	
Missing	4		
	Mean	*SD*	*Range*
Age (years)	51.83	11.34	27–75
MS disease severity[a]	4.35	2.53	1–9
Years since MS diagnosis	9.37	9.27	0–44

[a] Physician's Disease Steps Scale (score range 1–9)

Table 3 Descriptive statistics and results of univariate analyses (*N* = 126)

Outcomes	Pre-intervention		Post-intervention		Follow-up		Main effect (Time)			Post-hoc contrasts			
	Mean	(SD)	Mean	(SD)	Mean	(SD)	F	df	Partial η^2	Pre to Post (p)	Cohen's d	Post to Follow-up (p)	Cohen's d
Primary Outcome													
Total Distress	37.36	(11.77)	34.90	(7.65)	33.26	(6.31)	12.51**	1.65	.91	.027	.25	.023	.23
Depression	12.88	(4.87)	11.79	(3.57)	11.18	(3.06)	11.39**	1.87	.84	.014	.25	.148	.18
Anxiety	10.70	(3.60)	10.57	(2.29)	10.13	(1.73)	2.51	1.64	.20	1.000	.04	.081	.21
Stress	13.78	(4.78)	12.54	(2.98)	11.95	(2.51)	14.32**	1.51	.10	.009	.31	.035	.21
Secondary Outcomes													
Perceived Stress	27.43	(7.34)	24.94	(5.55)	23.75	(4.55)	21.45**	1.82	.15	.000	.38	.042	.23
QoL Mental health	53.80	(21.89)	61.29	(16.22)	64.54	(13.03)	20.04**	1.85	.14	.000	.39	.090	.22
QoL Physical health	44.93	(20.53)	48.62	(14.06)	55.37	(14.71)	20.86**	1.90	.14	.112	.21	.000	.47
Fatigue	16.56	(3.87)	16.02	(3.11)	15.15	(2.75)	8.97**	1.90	.07	.336	.15	.013	.30
Change mechanisms:													
Psychological Flexibility [a]	21.93	(10.69)	20.07	(7.68)	17.12	(5.51)	18.70**	1.83	.13	.099	.20	.000	.44
Self-Compassion	18.97	(4.73)	19.64	(3.59)	20.88	(3.14)	14.97**	1.78	.11	.259	.16	.000	.37
Mindfulness	76.63	(13.19)	80.22	(11.4)	83.18	(10.09)	20.28**	1.75	.14	.006	.29	.001	.27

QoL = quality of life; [a] Lower scores indicate greater psychological flexibility

*p < .05, **p < .001

Intervention Related Outcome Changes

Results of repeated measures ANOVAs on the ITT sample are summarised in Table 3. All analyses required Greenhouse-Geisser corrections. Bonferroni-corrected post-hoc comparisons are reported.

Primary Outcome There was a significant main effect of time for the primary outcome total distress $F(1, 65) = 12.51$, $p < .001$, $\eta p2 = .91$. Regarding the three distress dimensions, there were significant main effects of time on depression $F(1, 87) = 11.39$, $p < .001$, $\eta p2 = .84$ and stress $F(1, 51) = 14.32$, $p < .001$, $\eta p2 = .10$, but not on anxiety. Post hoc comparisons showed that from pre- to post-intervention there were statistically significant reductions in total distress, depression and stress. From post-intervention to follow-up there was a further significant reduction in total distress and stress.

Secondary Outcomes There were significant main effects of time on perceived stress $F(1, 82) = 21.45$, $p < .001$, $\eta p2 = .15$; mental health QoL $F(1, 85) = 20.04$, $p < .001$, $\eta p2 = .14$, physical health QoL $F(1, 90) = 20.86$, $p < .001$, $\eta p2 = .14$, and fatigue $F(1, 90) = 8.97$, $p < .001$, $\eta p2 = .07$. Post hoc comparisons showed that perceived stress decreased from pre- to post-intervention, and from post-intervention to follow-up. Mental health QoL only improved from pre- to post-intervention and physical health QoL only improved from post-intervention to follow-up. Significant decreases in fatigue were only evident post-intervention to follow-up.

Regarding the proposed change mechanisms, there were significant main effects of time for mindfulness $F(1, 75) = 20.28$, $p < .001$, $\eta p2 = .14$, self-compassion $F(1, 78) = 14.97$, $p < .001$, $\eta p2 = .11$ and psychological flexibility $F(1, 83) = 18.70$, $p < .001$, $\eta p2 = .13$. Post-hoc comparisons showed that only mindfulness improved from pre- to post-intervention, whereas all three proposed change mechanisms improved from post-intervention to follow-up.

Mediation Analyses

Temporal Mediation Statistically significant changes in the three proposed change mechanisms were examined as potential mediators of significant post-intervention to follow-up changes in the primary outcome of distress and the secondary outcomes of perceived stress, physical health QoL and fatigue. Mindfulness was the only proposed change mechanism that significantly changed pre- to post-intervention and was therefore the only putative mediator that could be used in a temporal mediation model. Effects were examined with post-intervention and follow-up scores for each significant outcome entered as the Y variable, mindfulness at pre-intervention and post-intervention inserted as M and the interval of time between measurements (post-intervention to follow-up) entered as X. Four models were tested (one for each significant outcome). One significant indirect effect emerged and is presented in Fig. 2. Specifically, increases in mindfulness from pre- to post-intervention mediated the changes in perceived stress from post-intervention to follow-up, $ab = -.45$, percentile CI [−0.94, −0.09].
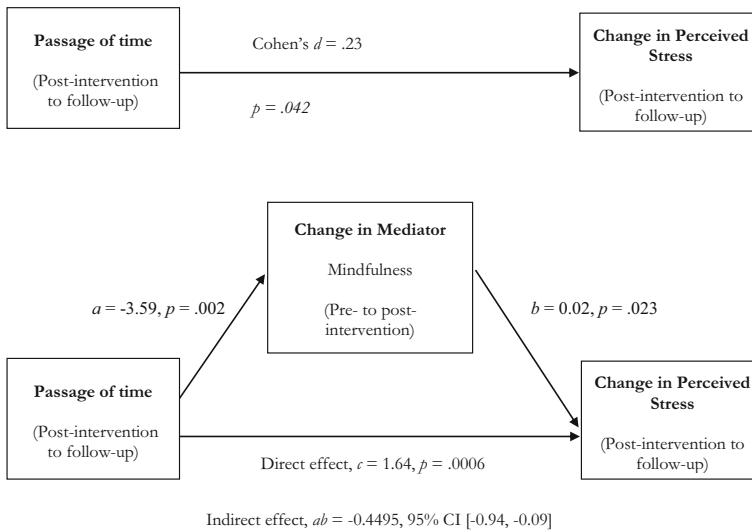
Fig. 2 Temporal mediation of mindfulness on perceived stress

Concurrent Mediation Concurrent mediation effects were also examined for pre- to post-intervention. One proposed change mechanism (mindfulness), and three outcomes (distress, perceived stress and mental health QoL) significantly improved pre- to post-intervention. The X variable was the passage of time (pre- to post-intervention), the Y variable was each outcome variable and the M variable was mindfulness. Results showed a significant indirect effect of pre- to post-intervention changes in mindfulness on pre- to post-intervention changes in distress ($ab = 1.39$, CI [0.42, 2.63]), perceived stress ($ab = 1.15$, CI [0.39, 2.02]), and mental health QoL ($ab = 2.22$, CI [−3.93, −0.71]).

Given that all three proposed change mechanisms significantly improved post-intervention to follow-up, concurrent mediation effects were examined for significant changes in distress, perceived stress, physical health QoL and fatigue from post-intervention to follow-up. Four concurrent mediational models were tested (one for each significant outcome), with the passage of time (post-intervention to-follow-up) entered as the X variable, proposed change mechanisms at post-intervention to follow-up the M variables and each significant outcome at post-intervention to follow-up entered as the Y variable. Table 4 presents the results of these mediation analyses. Results indicated that post-intervention to follow-up increases in self-compassion mediated improvements in distress, perceived stress, physical health QoL and fatigue, increases in mindfulness mediated physical health QoL, and greater psychological flexibility mediated improvements in distress and perceived stress.

Change in Outcomes Predicted by Socio-Demographics and Illness Factors

One-way ANCOVAs examined whether socio-demographics (age, meditation experience, education, employment) and illness factors (illness duration, course of MS, disease severity and disability) predicted post-intervention scores on the primary outcome of distress and the secondary outcomes, controlling for pre-intervention outcome scores.

Table 4 Concurrent mediation effects of post-intervention to follow-up changes in distress, perceived stress, physical health QoL and fatigue ($N = 126$)

Indirect effect	Point estimate	BCa 95% CI	
		Lower	Upper
Distress			
Self-compassion	**0.5609**	**0.1437**	**1.1261**
Mindfulness	0.0373	−0.2816	0.3068
Psychological Inflexibility	**0.4651**	**0.1344**	**0.8331**
Total Indirect Effect	1.0633	0.6073	1.5537
Perceived Stress			
Self-compassion	**0.8808**	**0.1360**	**1.8652**
Mindfulness	−0.0014	−0.6137	0.5307
Psychological Inflexibility	0.3998	−0.1453	1.0392
Total Indirect Effect	1.2792	0.6831	1.9686
Physical Health QoL			
Self-compassion	**−3.7710**	**−6.5258**	**−1.3554**
Mindfulness	**2.4652**	**0.4358**	**4.8881**
Psychological Inflexibility	0.0306	−2.4708	2.7583
Total Indirect Effect	−1.2753		
Fatigue			
Self-compassion	**0.4682**	**0.0364**	**1.0359**
Mindfulness	0.0557	−0.3510	0.4208
Psychological Inflexibility	−0.1309	−0.5695	0.3146
Total Indirect Effect	0.3930	0.0592	0.8283

Based on 5000 bootstrap samples. BCa = bias corrected and accelerated; CI = confidence interval

Significant mediation effects are highlighted in bold. The directions of the models' a paths (IV to mediators) and b paths (direct effects of mediators on DV) were consistent with the predictions

Education was significantly associated with improvements in fatigue ($F(3,121) = 3.75$, $p = .013$); however, post hoc tests showed no significant variations across the education levels. Disease severity was significantly associated with improvements in physical health QoL ($F(3,121) = 3.17$, $p = .046$). Post-hoc comparisons revealed physical health QoL was higher for those with mild compared to severe disease ($p = .040$).

Change in Outcomes Predicted by Home Practice

Regression analyses examined minutes of home mindfulness practice as a predictor of changes in primary and secondary outcomes at post-intervention. Amount of home practice emerged as a marginally significant predictor of mindfulness ($F(1,59) = 3.530$, $p = .065$; $R^2 = .056$; $\beta = .011$).

Sustained Program Feasibility

Program Offerings, Recruitment and Retention Between 2014 and 2018 a total of 21 mindfulness groups were conducted. Facilitator attendance records could not be used because of extensive missing records. For all groups, attendance at sessions one and five was recorded by MSQ. A total of 203 PwMS attended session one and 131 attended session five (65% retention).

Participant Engagement Completed weekly home practice records were submitted by 88 participants, however home practice records for only 61 participants could be linked with questionnaire identification codes. The range of total minutes completed was 15 to 1700 ($M = 439$, $SD = 297$) with an average of 110 min per week.

Facilitator Engagement Five groups were facilitated by registered psychologists working in the community and 16 were facilitated by postgraduate clinical psychology students.

Geographical Reach The mindfulness groups were conducted throughout Queensland: 15 in major cities, three in 'inner regional' locations and three in 'outer regional' locations. Venues were wheelchair accessible and included locations such as community halls, community centres, libraries, recreational centres and respite centres.

Participant Satisfaction and Feedback. A total of 86.6% ($n = 65$) participants provided ratings for each of the four items gauging the extent to which participants found the intervention helpful, enjoyable and useful and the degree to which they would recommended it to other PwMS. The mean rating for each of the four items ranged from 4.31 to 4.54 on a 5-point scale (1 = "strongly disagree" to 5 = "strongly agree"). All means were well above the mid-point and skewed towards higher ratings.

Thematic analysis of responses to the first two open-ended questions about the most helpful aspects of the program (98.6%; $n = 74$) and personal changes since attending the program (98.6%; $n = 74$), revealed overlapping themes; hence, the qualitative data from both questions were pooled. Eight themes emerged: increased present moment awareness ($n = 48$) (e.g., *I take more notice of things happening around me*), valuing the present moment ($n = 26$) (e.g., *I am able to enjoy so much more of my environment*), incorporating informal mindfulness into daily activities ($n = 14$) (e.g. *learning to practice mindfulness in everyday situations instead of having to set aside time to lie down and do it was practical and doable*), increase in distancing from unhelpful thoughts and emotions ($n = 12$) (e.g. *the ability to name a feeling and separate from it, rather than letting it consume me*), enhanced positive psychological states ($n = 43$) (e.g., *I am calmed and more relaxed)*, reduction in physical symptoms ($n = 33$) (e.g. *I have noticed an improvement in sleep and reduction in pain, am less reliant on medication to achieve sleep and relieve leg pain*), greater self-compassion ($n = 13$) (e.g. *I have learned to give myself some kindness and attention*), and appreciation of group connectedness ($n = 25$) (e.g., *I learnt a lot from others in the group. It was lovely to have a sense of sharing and community*).

Seventy-three (97.3%) participants responded to the question about how the program impacted their coping with MS. Six themes emerged: changed perspectives on living with MS ($n = 29$) (e.g. *I feel I have made a small space for this disease in my life,*

it will not define me and I will focus on the positives of today), management of MS related negative thoughts ($n = 10$) (e.g. *If I have negative thoughts about what might be in store for me in the future, I don't seem to get caught up in them*) and emotions ($n = 21$) (e.g. *it has eased my anxiety*), reactions to symptoms ($n = 16$) (e.g. *allows me to panic less about sensations I become aware of*), greater acceptance of MS ($n = 8$) (e.g. *I have moved towards acceptance of my post-diagnosis self*), and enhanced self-compassion ($n = 5$) (e.g. *I am caring for myself more and not feeling guilty when I am having a slow day*).

Sixty-three participants (84.0%) responded to the question about aspects of the program that should be changed. Themes included: no changes ($n = 33$), increase intervention duration ($n = 7$), modification of formal mindfulness exercises ($n = 6$) (e.g. *for people with chronic pain, the body scan early was too early in the course and very confronting*), inclusion of peaceful music ($n = 6$), more information on mindfulness theory and research ($n = 4$), and tighter management of negative group dynamics ($n = 8$).

Sixty participants (80.0%) responded to the final probe inviting further comments about the program. Responses included 'No' ($n = 12$), positive acknowledgements of the intervention experience and skills gained ($n = 38$), greater program dissemination ($n = 11$), and venue-related issues ($n = 4$).

Discussion

This study investigated the effectiveness and sustainability of a brief MBI for PwMS delivered in community locations. As predicted, participants showed improvements on the primary outcome distress, and all secondary outcomes (perceived stress, fatigue, QoL, mindfulness, self-compassion and psychological flexibility). Distress, perceived stress and mindfulness continued to improve post-intervention to follow-up. Improvements in fatigue, physical health QoL, self-compassion and psychological flexibility were delayed. Mindfulness emerged as a significant temporal mediator of decreases in perceived stress, and all three proposed change mechanisms were concurrent mediators of two or more of the outcomes. Finally, participant and facilitator engagement, number of programs conducted, geographical reach and participant feedback suggested community-based delivery of the Mindfulness for MS program on multiple occasions over a five-year period was feasible.

Improvements in the primary outcome distress and the secondary outcomes of perceived stress, fatigue and QoL in the current study reflect the results of the Mindfulness for MS pilot study (Spitzer & Pakenham, 2018), with the exception that in the pilot, physical health QoL and fatigue did not significantly improve. This may be due to the fact that the present study had a larger sample size and consequently greater statistical power. In addition, the improvements in distress, perceived stress, fatigue and QoL in the present study reflect findings from other MBI studies for PwMS (e.g., Grossman et al., 2010; Bogosian et al., 2015; Cavalera et al., 2019; Carletto et al., 2017; Senders et al., 2018; Simpson et al., 2017).

Notably, non-significant reductions in anxiety were observed in both the current and pilot studies (Spitzer & Pakenham, 2018). In contrast, other studies of MBIs for PwMS

have demonstrated reduced anxiety symptoms at post-intervention and follow-up assessments (Cavalera et al., 2019; Hoogerwerf et al., 2017; Simpson et al., 2017). This discrepancy may be due to the possible overlap between MS and anxiety symptoms in the distress measure used in the current study. Another explanation is that the intervention may be too short. Other MBI studies that have found improvements in anxiety in PwMS have been of longer duration (Hoogerwerf et al., 2017; Gilbertson & Klatt, 2017; Carletto et al., 2017). The Mindfulness for MS program is the briefest published MBI for PwMS.

The improvements in the proposed change mechanisms are consistent with findings from prior research on MBIs for PwMS (e.g., Bogosian et al., 2016; Spitzer & Pakenham, 2018). Interestingly, mindfulness was the only proposed change mechanism to significantly increase from pre- to post-intervention, with ongoing improvement at follow-up. Improvements in self-compassion and psychological flexibility were delayed. The delayed improvement in self-compassion is consistent with results of Bogosian et al.'s (2016) study. These findings align with the theoretical proposal that increased mindfulness is a requirement for the development of self-compassion (Neff, 2003) and data that suggests a sequential process of meditation experience, followed by increased mindfulness, leading to increased self-compassion (Bergen-Cico & Cheon, 2014). It appears that the consolidation of mindfulness skills is required to induce improvements in both self-compassion and psychological flexibility.

Temporal mediational analyses revealed initial improvements in mindfulness mediated subsequent reductions in perceived stress. This finding is consistent with results from Bogosian et al.'s (2015) study which showed that mindfulness mediated MBI associated reductions in distress in PwMS. Although concurrent mediational analyses are not as robust as temporal mediation, results suggest that self-compassion and psychological flexibility may also function as change mechanisms in MBIs for PwMS. These mediational findings are consistent with the results of an MBI for nurses which showed that mindfulness, self-compassion and psychological flexibility were active change mechanisms (Duarte & Pinto-Gouveia, 2017).

None of the socio-demographics and only one illness factor predicted improvements on the primary and secondary outcomes. Less disease severity predicted greater improvement in physical health QoL. However, disease severity has not been identified as a consistent predictor of improvement in other MBI studies of PwMS (Cavalera et al., 2019; Grossman et al., 2010; Hoogerwerf et al., 2017). This discrepancy may be due to measurement differences across studies.

Home practice was not related to greater improvement in outcomes. In prior MBIs for PwMS, non-significant (Gilbertson & Klatt, 2017) and significant (Grossman et al., 2010) associations between higher home practice completion and greater improvement on psychosocial outcomes have been found. It should be noted that in the present study the sample size for the home practice analyses was relatively small because only 60.7% completed the forms and 18.6% ($n = 27$) of completed forms had identification code errors.

Data supported the sustained feasibility and implementation of the Mindfulness for MS program in the community over five years. A total of 21 groups were conducted over the evaluation period. The retention rate was 65%, which is similar to that of previous studies (e.g., 60% Simpson et al., 2017; 73.7%, Bogosian et al., 2015; 85% Senders et al., 2018).

The program was effectively managed by, and offered through, the peak MS community-based organisation in Queensland. The partnership between the university and MSQ contributed to the sustainability of program delivery over the longer term. In terms of facilitator engagement, groups were facilitated by postgraduate students ($n = 16$) and registered psychologists ($n = 5$). Regarding participant engagement, although the percentage of returned home practice data was low, an average of 110 min of home practice was undertaken per week. This is higher than levels of weekly home practice recorded in previous studies of MBIs for PwMS, (e.g. 32.5 min Simpson et al., 2017; 29.2 min Grossman et al., 2010).

The overall positive intervention feedback indicated high levels of participant satisfaction. The qualitative data analyses confirmed participant improvements in areas assessed by study measures and showed gains in other areas not directly assessed by them (e.g. sleep, changed perspectives on living with MS, increased acceptance of the diagnosis, and better management of negative thoughts, emotions and reactivity to MS symptoms).

Importantly, participants suggested improvements for the Mindfulness for MS program, including: increased information provided about mindfulness meditation, more group discussion time, better control of negative group dynamics, more debriefing of the body scan exercise, extra sessions or a follow-up program, and inclusion of relaxation music.

Largely due to the pragmatic health care context of this research, the study has some methodological limitations. First, the non-random sampling and an under-representation of people with severe MS limits the generalisability of findings. Second, given the absence of a control group, other factors beyond the intervention may have led to the observed gains, and we are unable to make conclusions about the efficacy of the program. Third, the relatively high number of tests increases the risk of Type 1 error; however, most improvements on the outcomes were significant at $p \leq 0.01$, and most effect sizes fell in the small range. Forth, session attendance data was only available for the first and last sessions. Based on the final intervention session attendance data, the drop-out rate was 35%; however, other studies of MBIs for PwMS have reported similar drop-out rates (29% Hoogerwerf et al., 2017; 26% Bogosian et al., 2015). A fifth limitation is the relatively high number of participants who failed to complete the post-intervention (45.5%) and follow-up (61%) assessments. Sixth, only 42% of participants provided useable home practice records. We analysed this data as a means of providing preliminary findings related to the role of home mindfulness practice. Seventh, the study protocol drop-out appeared biased towards those with poorer physical and mental health QoL. Finally, intervention fidelity was not assessed. Although program facilitators followed a program manual and session plan scripts, it is not possible to conclusively determine whether they strictly adhered to the intervention protocols. Future evaluations of the Mindfulness for MS program should include a control group, longer follow-up assessments and different methods of collecting home practice data (e.g., via phone or email).

In conclusion, results of the present study support the effectiveness of the Mindfulness for MS program in improving distress, perceived stress, fatigue and QoL, and in strengthening protective factors, mindfulness, self-compassion and psychological flexibility in PwMS. These results are noteworthy given the high rates of distress, perceived stress, and fatigue and lower QoL in PwMS. The Mindfulness for MS program is the

briefest published MBI for PwMS and yet the associated improvements across a wide range of mental health dimensions are comparable to those of prior evaluations of lengthier MBIs for PwMS. Findings contribute to our knowledge of MBI change mechanisms suggesting that increases in mindfulness, self-compassion and psychological flexibility mediate MBI intervention effects on psychosocial outcomes for PwMS. Most intervention effects were not influenced by socio-demographics or illness factors, which suggests the program has broad applicability across the MS community. This is the first study of a brief group MBI for PwMS delivered in community locations through a frontline service over a lengthy period. Data suggest the program can be successfully sustained in this context. This manualised program could be modified for individual delivery, or used to augment standard medical and psychological interventions for PwMS. The partnership between the university and the community-based organisation appears to be a key element in the sustained delivery of the program. This service delivery approach may serve as a model for future delivery of this and similar interventions in the community.

Declarations

Disclosure of Potential Conflicts of Interest   As a staff member of The University of Queensland and co-Author of the Mindfulness for MS program, KP receives royalties from UniQuest for commercial (not research) licensing arrangements entered into by third parties who want to deliver the program.

Human Research Ethics Approval & Informed Consent   All research procedures (including informed consent) were in accordance with the ethical standards of The University of Queensland's ethical clearance research committee and with the 1964 Declaration of Helsinki and its later amendments.

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