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Abstract

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Keywords	Parkinson's disease; Mindfulness; Depression; Anxiety; Stress; Coping.
Corresponding Author	Kelly Birtwell
Order of Authors	Kelly Birtwell, Linda Dubrow-Marshall, Rod Dubrow-Marshall, Tim Duerden, Annette Dunn
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A mixed methods evaluation of a Mindfulness-Based Stress Reduction course for people with Parkinson's disease

Kelly Birtwell, MSc,^{1*} Linda Dubrow-Marshall, PhD,¹ Rod Dubrow-Marshall, PhD,¹ Tim Duerden, MBBS,^{1,2} and Annette Dunn, MSc²

¹University of Salford, The Crescent, Salford, M5 4WT, UK.

²Integrated Mindfulness, 145 Radcliffe New Road, Whitefield, Manchester, M45 7RP, UK.

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*Corresponding author. E-mail address: Kelly.birtwell@outlook.com

Present address: The University of Manchester, Centre for Primary Care, Williamson Building, Oxford Rd., Manchester, M13 9PL, UK.

Author contributions: KB: designed and executed the study, analysed the data and wrote the paper. LDM: collaborated with the design of the study, assisted with data analyses and collaborated in the writing and editing of the final manuscript. RDM: assisted with data analyses and collaborated in the writing and editing of the final manuscript. TD: collaborated with the design of the study, delivered the MBSR intervention and collaborated in the writing and editing of the final manuscript. AD: collaborated with the design of the study, delivered the MBSR intervention and collaborated in the writing and editing of the final manuscript.

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Conclusion: This study supports previous preliminary findings that mindfulness-based interventions could benefit people with Parkinson's experiencing non-motor symptoms. Further research using larger sample sizes, a control group, and a longer follow-up period is required.

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1. Introduction

In the UK approximately 120,000 people have Parkinson's disease¹. It is one of the most common neurodegenerative disorders, second only to Alzheimer's disease².

Although it is predominantly considered a movement disorder, people with Parkinson's often experience non-motor symptoms (NMS), which can vary greatly from person to person. NMS include neuropsychiatric problems, autonomic dysfunction, sleep disturbance and sensory symptoms.

Anxiety and depression are the most common neuropsychiatric problems with approximately 40-45% of patients experiencing depression, and up to 40% experiencing anxiety^{1,3,4}. Anxiety is often associated with immobility and can make other PD symptoms worse⁵. It is common for people with Parkinson's to fear being stigmatised, and more than one third of patients have felt it necessary to lie about their diagnosis and try to hide their symptoms⁶. Non-motor symptoms can have a significant effect on quality of life, as well as disability and activities of daily living^{7,8,9,10,11,12,13,14}. According to the current evidence more effective diagnosis and treatment of Parkinson's NMS is needed^{13,15,16}.

Recent research has suggested that Mindfulness-Based Interventions (MBIs) may be effective for people with Parkinson's disease experiencing NMS. Fitzpatrick, Simpson and Smith (2010)¹⁷ reported positive changes to coping responses, including a reduction in avoidance, in participants of an MBI. Findings have also indicated a relationship between mindfulness and reduced anxiety and depression for patients and their partners¹⁸. More recently there have been reports of improvements in motor symptoms in people with PD following attendance of a mindfulness course¹⁹ as well as improvements in symptoms of depression for both patients and carers, and improvements in emotional and cognitive symptoms of PD²⁰.

Mindfulness has been defined as “Paying attention in a particular way: on purpose, in the present moment and non-judgementally”²¹. Mindfulness can be taught to people individually, for example as part of psychotherapy²² or as a group-based course such as Mindfulness-Based Stress Reduction (MBSR)²³ or Mindfulness-Based Cognitive Therapy (MBCT)²⁴. MBCT and MBSR programmes consist of formal mindfulness practices such as the body scan or a sitting meditation as well as informal mindfulness practice which involves bringing mindful awareness to everyday activities such as eating or washing the dishes. The increased awareness of direct experience and development of skills to support cognitive defusion (seeing thoughts as passing mental events)²⁵, can enable people to respond more skilfully to experiences. Course participants learn to recognise their own automatic habits and reactions, thus increasing opportunities to make wiser choices rather than reacting to experiences automatically.

Mindfulness-Based Stress Reduction is suitable for the general population with various physical and mental health problems²³. As Parkinson’s disease is a long-term condition with both physical and psychological symptoms, MBSR may be particularly suitable for this client group.

The aim of this study was to evaluate the impact of a Mindfulness-Based Stress Reduction course on depression, anxiety and stress in people with Parkinson’s. Although this was a small study the combination of quantitative and qualitative data provide significant insights into the patient experience.

2. Materials and Method

Patient and public involvement:

Two patient advisors provided feedback on the study design, participant information leaflet and outcome measures. Changes were made based on their feedback and

they also helped to choose the measure of mindful awareness. One patient advisor highlighted the stigma associated with the word 'disease' and suggested using 'Parkinson's' wherever possible rather than 'Parkinson's disease'. The advisors also highlighted the on-off effects of L-dopa medication which could make it challenging for some participants to attend the mindfulness course, depending on their drug regimen and timing of 'off' periods. Patients may suddenly switch from normal movement where symptoms are under control (being 'on') to the reappearance of symptoms or immobility (being 'off', where there may be a loss of effect before the next dose).

2.1 Participants:

Patients were recruited from a local hospital and were eligible for the study if they:

1. Had a diagnosis of Idiopathic Parkinson's disease according to the Parkinson's UK Brain Bank criteria²⁶.
2. Identified themselves as experiencing depression, anxiety, stress, or difficulty coping with PD.

'Difficulty coping with PD' was an inclusion criterion as some patients may experience symptoms of depression, anxiety or stress, but may not necessarily identify themselves as being 'depressed', 'anxious' or 'stressed'. Patients were assessed by the researcher as part of the standard procedure for MBSR courses, to ensure the course was suitable for them and to identify any risks.

Thirteen patients were recruited to the study and seven withdrew. Four participants withdrew before the start of the course due to scheduling conflicts (e.g. work) or ill health. Three participants withdrew following the first session due to work, ill health, and one person stated they did not wish to continue with the course.

The participants who withdrew included the oldest and youngest patients (aged 78 and 47), they had more complex health conditions and had been living with Parkinson's disease for longer than those who continued in the study. Five of the six participants who completed the MBSR course were male. Four participants were retired, one was working and one was not working. According to the Hoehn and Yahr staging of Parkinson's disease participants were mild to moderate and still independent. Characteristics and PD history are summarised in table 1 below.

Table 1: participant characteristics and PD history

	mean	(SD)	range
Age (years)	67.96	(5.64)	60.8 – 72.9
Age at disease onset (years)	59.18	(7.40)	51.2 – 70.5
Age at diagnosis (years)	60.76	(6.33)	55.2 – 71.0
Disease duration (years)	8.83	(5.48)	2.2 – 18.4
Hoehn & Yahr stage (1-5)	2.33	(0.68)	1.5 – 3.0

2.2 Intervention:

The MBSR course followed the standard 8-week programme of mindfulness meditation, stories, poetry, metaphors, mindful movement, yoga, and information on the physiological and psychological basis of stress. An all-day silent retreat was not included, for reasons explained below. Participants were asked to complete up to 45 minutes of daily home practice using CDs and worksheets provided. The course was run by experienced MBSR teachers who met the UK Network for Mindfulness-Based Teachers Good practice guidelines for teaching mindfulness-based courses²⁷.

Following discussions with the patient advisors, the researcher and MBSR teachers agreed to adapt the course. People with Parkinson's may experience a lot of pain so the duration of the body scan was shortened to approximately 15-20 minutes as it was felt that focussing on the body for longer could be emotionally challenging. It was made clear that practices involving movement or yoga were voluntary and participants should consider their own safety, taking care to work within their own limits to avoid strain or injury.

Some people with Parkinson's struggle to concentrate for long periods of time so practices such as the sitting meditation (which could be 30-45 minutes long) were shortened. A break was also introduced half way through the sessions. It was felt the all-day silent retreat may be too arduous so this was discussed with the course participants and it was agreed to forgo this session.

Previous mindfulness and Parkinson's studies have varied in terms of adapting standardised courses. Fitzpatrick et al. (2010)¹⁷ did not adapt the MBCT course however it was reiterated to participants that practices were voluntary and they should recognise their own limits and not engage in any physical exercises which could cause them physical harm or strain. Sephton et al. (2011)²⁸ adapted the practices throughout their MBSR course to suit the abilities of the participants, for example the option to sit in a chair for movement exercises that would sometimes be done on the floor was offered (S. E. Sephton, personal correspondence, 7 June 2013). Cash et al. (2015)²⁰ shortened the duration of sessions and practices, and also encouraged participants to work within their own limits and engage in gentle movement while sitting, if preferred.

2.3 Outcome measures:

Participant self-evaluation of depression, anxiety and stress was measured using the Depression Anxiety and Stress Scale, short version (DASS-21)²⁹. The DASS-21 is a validated set of three scales for measuring changes to levels of depression, anxiety and stress over time³⁰. It is reliable and valid when used in the elderly population³¹, and has been used in previous mindfulness studies^{17,32,33,34}.

Patient wellbeing and stigma were measured using the Parkinson's Disease Questionnaire 39 (PDQ39)³⁵. The PDQ39 is a disease-specific rating scale for PD, covering 8 dimensions: mobility, Activities of Daily Living, emotional wellbeing, stigma, social support, cognition, communication and bodily discomfort. The PDQ39 is the most widely used disease-specific quality of life rating scale for PD and has been fully validated^{35,36}. In a sample of 728 patients living with Parkinson's, Jenkinson et al. (2012)³⁷ reported an increase of 2-5 points at 6-month follow-up for each dimension except social support. This gives an indication of worsening of symptoms and disease progression in the general Parkinson's population. The PDQ39 was used by Advocat et al. (2013)³² for their mindfulness and Parkinson's study.

Patient levels of mindful awareness were measured using the Mindful Attention Awareness Scale (MAAS)³⁸. The MAAS is a 15-item validated scale suitable for patients without previous experience of meditation. It has good predictive validity and provides an overall rating of mindful awareness^{39,40}. Subsequent to this study, a recent meta-analysis of the ten most frequently used scales concluded that *"Investigators need to proceed cautiously before optimizing any mindfulness intervention based on the existing scales."* (Park, Reilly-Spong & Gross, 2013, p. 2639)⁴¹. This has major implications as it is standard practice in the clinical research of mindfulness to correlate outcomes with such scales.

Patient demographics and medical history were recorded at baseline, along with the Hoehn and Yahr stage⁴². The Hoehn and Yahr is a standard scale used to assess the severity of PD. Scores range from 1-5 with 1 indicating problems on one side of the body and 5 indicating someone reliant on a wheelchair or bedbound and requiring total assistance. Any changes to medication were recorded in follow-up questionnaires.

Follow-up questionnaires designed specifically for this study were administered at weeks 8 and 16. Participants were asked if the course had made any difference to their life, what they would tell other people with Parkinson's about MBSR, which practices they were committed to continuing, and which practices (if any) they were still practising at week 16.

2.4 Procedure:

Following ethical and regulatory approval, patients were recruited from a local Acute Hospital in response to a poster in the outpatient department or referral from the Principal Investigator, a Consultant Physician with a special interest in movement disorders. All participants gave informed consent and baseline assessments were administered by a researcher who was not involved in the delivery of the MBSR course. Questionnaires at week 8 and week 16 were completed by participants at home and returned by post.

2.5 Data analysis:

Participants who attended 6 or more MBSR sessions were included in the statistical analysis. One-way within subjects repeated measures analysis of variance (ANOVA) was employed to assess changes in symptoms as measured by the DASS-21, PDQ39 and MAAS.

Qualitative questions from the follow-up questionnaires were analysed using thematic analysis, as described by Braun and Clarke (2006)⁴³. The first author coded the participant responses and collated the codes into themes. The codes and themes were corroborated by the second author. Themes were based on prevalence across the data set as well as the importance and relevance to the research aims⁴³.

3. Findings

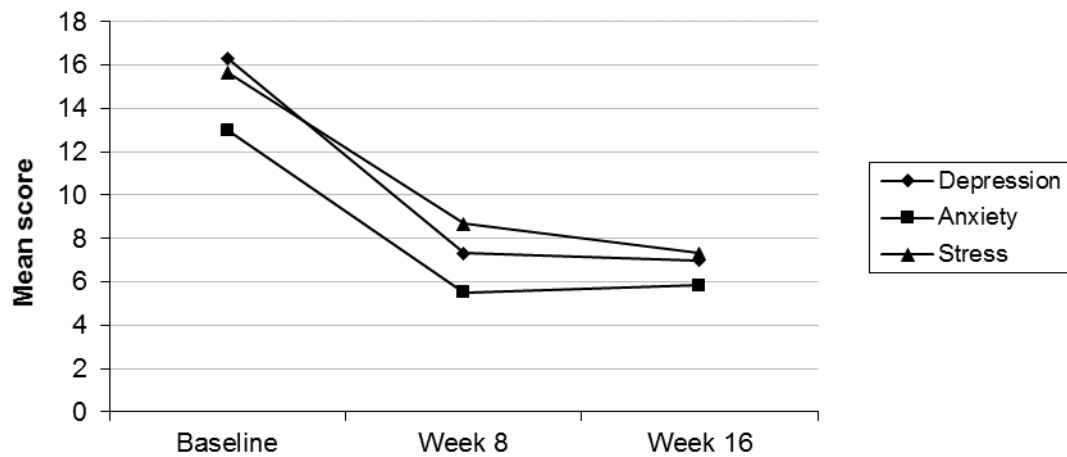
3.1 Quantitative data

The average number of MBSR classes attended by participants was 7.3 (range 6-8). The mean scores for all three DASS-21 scales decreased to within normal levels at week 8 and week 16 follow-up (see table 2 and figure 1 below; score range = 0-42). Severity categories are taken from Lovibond and Lovibond (1995)²⁹.

Table 2: DASS-21 mean score & severity category, (SD), ranges

	Baseline	Wk8	Wk16
Depression	16.33 moderate	7.33 normal	7.00 normal
	(7.31)	(3.62)	(7.21)
	8-26	3-13	0-18
Anxiety	13.00 moderate	5.50 normal	5.83 normal
	(7.56)	(3.02)	(5.53)
	4-20	1-9	0-15
Stress	15.67 mild	8.67 normal	7.33 normal
	(9.25)	(2.81)	(6.66)
	2-26	5-12	0-19

Figure 1: DASS-21 mean follow-up scores



For each of the scales for which analysis of variance was conducted the Mauchly assumption of sphericity was satisfied ($p > 0.05$) thus allowing for the univariate analysis of variance for the effect of the Mindfulness-Based Stress Reduction intervention over the time points to be conducted and reported. The main effect reported on each occasion is adjusted using the Greenhouse-Geisser epsilon to reflect the small sample size in this study.

For the stress subscale of the DASS-21 the repeated measures analysis of variance result showed a significant main effect of the intervention over time: $F(2, 10) = 6.43$, $p = 0.021$. Contrast analysis performed between the means for the different time points shows a significant difference between the baseline and week 8 ($F(1, 5) = 6.93$, $p = 0.046$) and between the baseline and week 16 ($F(1, 5) = 9.164$, $p = 0.029$) but a non-significant difference between week 8 and week 16 ($F(1, 5) = 0.440$, $p = 0.537$).

For the anxiety subscale of the DASS-21 the results showed a significant main effect of the intervention over time: $F(2, 10) = 6.17$, $p = 0.019$. Contrast analysis performed between the means for the different time points shows a significant difference

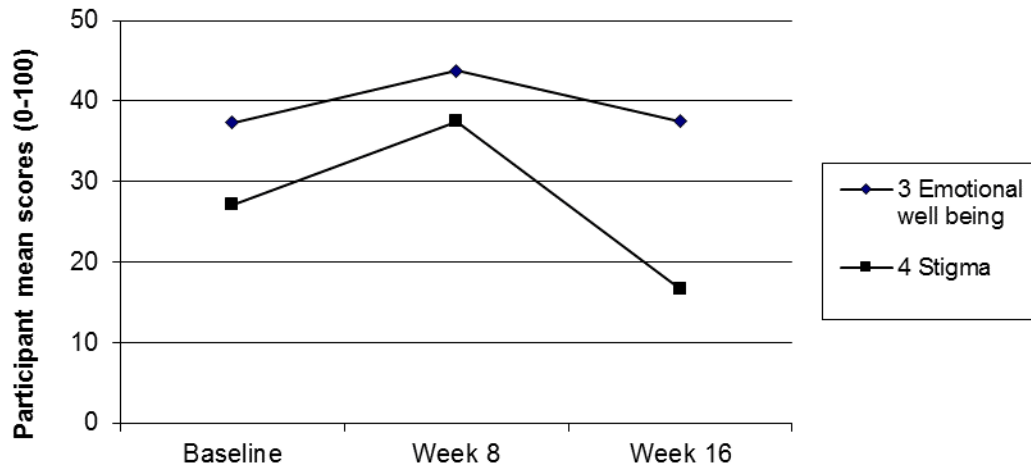
between the baseline and week 8 ($F(1, 5) = 11.28, p=0.02$) and between the baseline and week 16 ($F(1, 5) = 7.67, p = 0.039$) but a non-significant difference between week 8 and week 16 ($F(1, 5) = 0.19, p=0.895$).

For the depression subscale of the DASS-21 the results showed a significant main effect of the intervention over time: $F(2, 10) = 7.95, p=0.022$. Contrast analysis performed between the means for the different time points show a significant difference between the baseline and week 8 ($F(1, 5) = 22.95, p=0.005$) and between the baseline and week 16 ($F(1, 5) = 7.438, p=0.041$) but a non-significant difference between week 8 and week 16 ($F(1, 5) = 0.19, p=0.896$).

Taken together these results indicate a significant effect of the Mindfulness-Based Stress Reduction intervention on the sub-scales of the DASS for this sample of patients, with a significant reduction in stress, anxiety and depression in weeks 8 and 16 of the intervention compared to the reported pre-intervention baseline level.

Participants reported problems across all dimensions of the PDQ39 at baseline. Most problems were experienced with mobility and activities of daily living and fewer problems were reported with social support and stigma. The dimension of emotional wellbeing had the third highest score of the eight dimensions. Mean scores for the dimensions of emotional wellbeing and stigma are illustrated in figure 2. Scores range from 0 indicating no problem at all, to 100 indicating the maximum level of problem.

Figure 2: PDQ39 mean scores



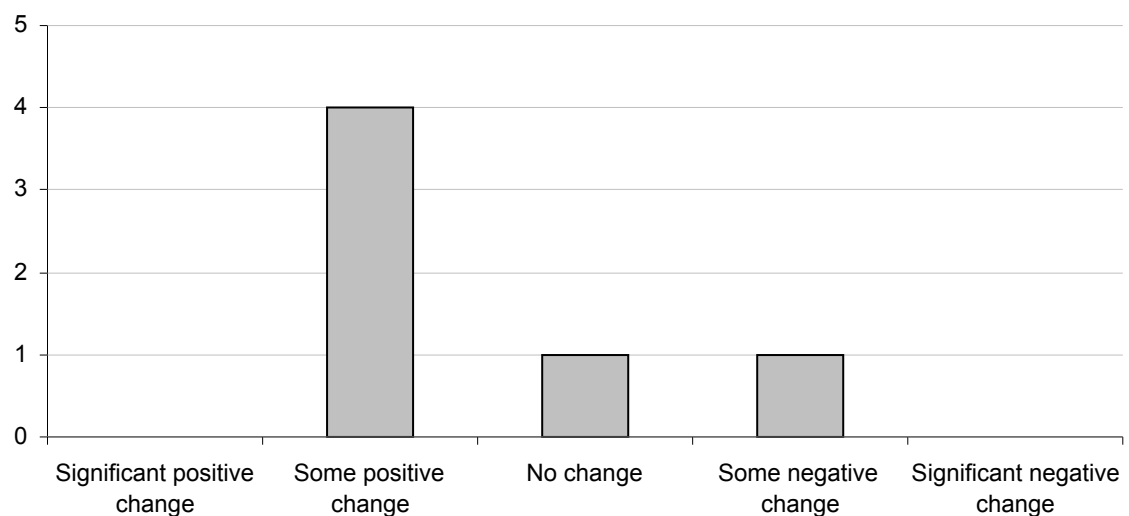
For both the wellbeing and stigma dimensions of the PDQ39 the Mauchly's test indicated that the assumption of sphericity was met ($p > 0.05$) thus allowing for a univariate repeated measures analysis of variance for the intervention effect to be conducted and reported (with the Greenhouse Geisser epsilon adjustment reported given the small sample size). The result for wellbeing showed the main effect of the intervention over time was not significant: $F(2, 10) = 0.95$, $p = 0.416$ thus indicating that the Mindfulness-Based Stress Reduction intervention did not have a significant effect on the PDQ39 measure of wellbeing for this sample.

For the stigma dimension of the PDQ39 the results showed a significant main effect of the intervention over time: $F(2, 10) = 4.73$, $p = 0.048$. Contrast analysis performed between the means for the different time points show a significant difference between week 8 and week 16 ($F(1, 5) = 6.75$, $p = 0.048$) but non-significant differences between the baseline and week 8 ($F(1, 5) = 2.33$, $p = 0.187$) and between the baseline and week 16 ($F(1, 5) = 3.98$, $p = 0.102$) thus indicating that stigma, as measured by the PDQ39, appears to be unaffected by the mindfulness based stress reduction intervention by the end of the time period for this sample, after an initial (if non-significant) rise in stigma at week 8.

Self-reported mindfulness as measured by the MAAS showed little change at week 8 and week 16 compared to the baseline time point. Scores at baseline ranged from 2 – 5, with a mean of 3.83 (SD = 1.17). The score range for the MAAS is 1-6, with higher scores indicating increased mindful awareness. Mauchly's test indicated that the assumption of sphericity was met ($p > 0.05$) and the results of a univariate repeated measures analysis of variance showed the main effect of the intervention over time was not significant: $F(2, 10) = 0.05$, $p = 0.087$ (adjusted by the Greenhouse Geisser epsilon for the small sample size) indicating that the level of self-reported mindfulness was not significantly affected by the Mindfulness-Based Stress Reduction intervention for this sample.

In the week-8 follow-up questionnaire four of the six participants reported some positive change in their experience of living with Parkinson's, as illustrated in figure 3 below.

Figure 3: Follow-up questionnaire 1: Has your experience of living with Parkinson's changed at all since attending the MBSR course?

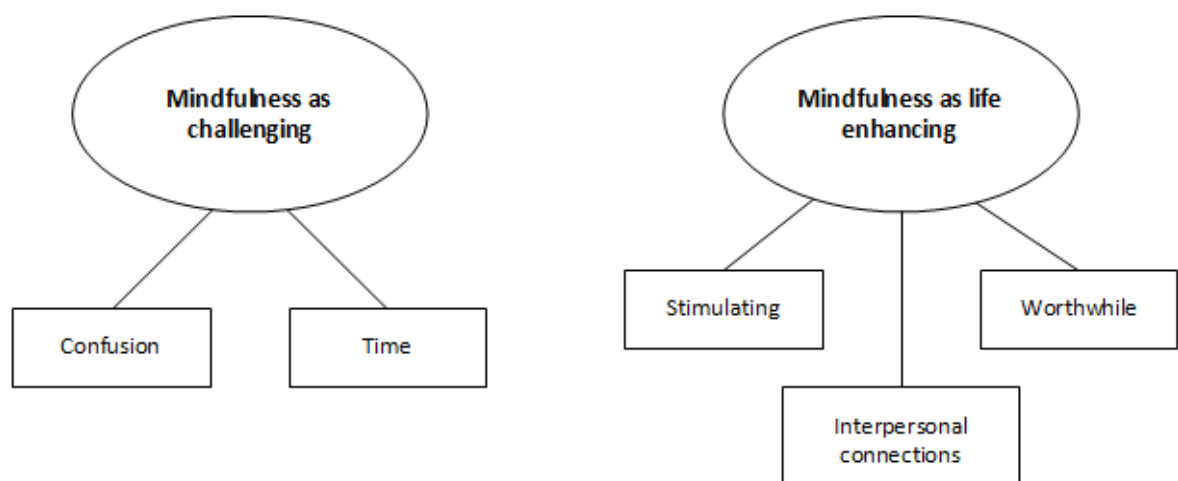


At week 8, participants reported they were most committed to continuing to practice the body scan and breathing space / mindfulness of the breath. At week 16, three of the six participants stated they were still practising mindfulness. The exercises practiced most often were breathing practices and focussing on the hands. Participants reported difficulties in continuing to practice due to time and other commitments.

3.2 Thematic analysis

Two main themes were identified from responses to the week 8 and week 16 follow-up questionnaires: mindfulness as challenging, and mindfulness as life enhancing. Each theme had a number of subthemes, as illustrated in figure 4 below.

Figure 4: Thematic map



Mindfulness as challenging: confusion

Participants reported confusion regarding some of the mindfulness concepts, aims of the practices, terminology used, and a need for fuller explanations earlier on in the course:

“Try to explain at an early point in the course the relevant aim of the practice.”

“Weeks 1-3 seemed confusing and somewhat abstract.”

“Find another word to use rather than 'sensation'. I found this difficult to relate to the situations we were asked to imagine. I was expecting something out of the ordinary.”

Mindfulness as challenging: time

Participants reported a desire to continue practicing mindfulness yet found this challenging due to limited time and other competing commitments:

“I enjoyed the course but due to personal circumstances I have not been able to give it my attention.”

“Not as often as I should.” [in response to *are you still practicing?*]

“Due to work commitments I am very tired when I finish for the day and just fall asleep.”

Mindfulness as life-enhancing: stimulating

Participants had no prior experience and very little prior knowledge of mindfulness and stated they found the course interesting and stimulating:

“Difficult, thought provoking and stimulating.”

“Prepare to be stimulated in an unusual way.”

“Enlightening but probably 40 years too late to make a big difference to me.”

Mindfulness as life-enhancing: worthwhile

Participants found the course worthwhile and interesting, and in spite of some challenges all participants in the study said they would recommend the MBSR course to others:

“I thought it was excellent and well worthwhile.”

“I found the course very interesting and well worth trying.”

"I would tell them not to be put off too soon, as its relevance takes some time to become obvious." [in response to *what would you tell others about the course?*]

Mindfulness as life-enhancing: interpersonal connections

Participants reported they enjoyed meeting other people with Parkinson's disease and they valued the support from the teachers:

"It added to the benefit of the course that one could meet other Parkinson's sufferers and compare each others thoughts and concerns about the course."

"Yes get involved because it's made me think about things and realise I'm not on my own."

"I enjoyed meeting other people, but I wasn't sure the course was for me."

"The tutors were ideal in keeping your attention giving a degree of confidence in this subject".

4. Discussion

Changes in two of the three quantitative measures were observed in patients with Parkinson's disease after attending an eight-week Mindfulness-Based Stress Reduction course. There were significant improvements in depression, anxiety and stress as measured by the DASS-21, the primary outcome measure for this study. Mean scores for all three subscales fell to within normal levels at week 8 and week 16 indicating a significant effect of the Mindfulness-Based Stress Reduction intervention. The wellbeing and stigma dimensions of the PDQ39 were chosen as the secondary outcomes for this study. The findings revealed a significant effect of time on the dimension of stigma, however this did not indicate a significant effect of the intervention as the significant change was between weeks 8 and 16, following the end of the intervention, and there was no significant change in stigma at either of those measurement points compared to the baseline. Additionally, changes in the dimension of wellbeing were not significant. There was little change in self-reported

mindfulness as measured by the Mindful Attention Awareness Scale. In qualitative follow-up questionnaires two thirds of participants reported some positive change in their experience of living with Parkinson's disease since attending the course and all participants said they would recommend the course to other people living with Parkinson's. Thematic analysis revealed participants experienced the mindfulness course as challenging as well as life-enhancing.

Statistical analysis revealed inconsistencies between the results of the wellbeing dimension of the PDQ39 which showed a temporary worsening of symptoms (although not significant) and the DASS-21 which showed significant improvements. The wellbeing dimension of the PDQ39 consists of only 6 questions whereas the DASS-21 consists of 21 questions across the three scales. The variance in the results of these measures could therefore be due to a difference in the sensitivity of the scales: it is possible the DASS-21 is a more sensitive measure of wellbeing than the PDQ39.

Interestingly, although there was a significant reduction in scores on the DASS-21 subscales, additional time (to week 16) does not appear to significantly add to this effect. This suggests the effect of the intervention does not appear to add significant benefit after the intervention has ended, indicating that the intervention may need to continue in order for significant additional benefit to accrue. Nevertheless, the effect of the intervention was significant at week 16, and levels of depression, anxiety and stress had significantly improved since baseline. These findings may be further explained by responses to the week 16 qualitative follow-up questionnaires. Participants reported they had experienced difficulties in continuing to practice mindfulness following the end of the intervention and only three out of the six participants stated they were still practicing. Continuing to practice may result in

benefits continuing to accrue so methods to support the maintenance of mindfulness practice are to be encouraged.

Self-reported mindfulness as measured by the MAAS was higher than expected at baseline. Scores decreased slightly at week 8 then increased again at week 16, with higher scores indicating increased mindful awareness. This was unexpected and differs from the pattern of MAAS results reported by Cusens, Duggan, Thorne, and Burch (2010)⁴⁴ from their study of a Breathworks mindfulness pain management course. They reported a mean of 3.35 (SD = 0.66) at timepoint 1 and 4.09 (SD = 0.62) at timepoint 2 (post-course) in a sample of 12 participants. The difference in these patterns of results could be explained by the selection of the sample and the participants' prior understanding of mindfulness. Cusens et al. (2010)⁴⁴ selected their sample from people registering for a Breathworks course. The participants had located the course themselves and registered using their own initiative, rather than being approached and informed about the course by a researcher. This could imply some prior knowledge and understanding of the concept of mindfulness. The mean age of participants was 46.7 years compared to 67.96 in this study, which could also have been a factor. The people with Parkinson's who participated in this study had no prior knowledge of mindfulness. Although all participants were provided with a Participant Information Leaflet containing information about the mindfulness course and they engaged in a thorough discussion with the researcher, it is possible that they did not fully understand the concepts of mindfulness and this could be reflected in the baseline MAAS scores. This view is supported by the findings of Smith, Graham, and Senthinathan (2007)⁴⁵ from their qualitative study of an MBCT course for older people with recurring depression:

"Several participants who at assessment thought they understood the aims of the course, said post-course that they had not understood them beforehand. We think this reflects the inherent difficulty of explaining mindfulness meditation verbally. It is

after all designed partly to circumvent the verbal dominance of our consciousness.”

(Smith, Graham, & Senthinathan, 2007, p.355)

The MAAS questionnaire has also been criticised for being a narrow measure of mindfulness with a focus on the element of attention, and for phrasing questions negatively³⁹. A broader understanding of participant experiences of mindfulness may be captured by a multi-faceted questionnaire such as the Five Facet Mindfulness Questionnaire (FFMQ)⁴⁶ which assesses five components of mindfulness: nonreactivity to inner experience, observing, acting with awareness, describing, and nonjudging of experience. Alternatively, a measure such as the AAQ-II (Acceptance and Action Questionnaire)⁴⁷ could be considered. The AAQ-II measures psychological flexibility, the “willingness to experience (i.e., not alter the form, frequency, or sensitivity of) unwanted private events, in the pursuit of one’s values and goals” (Bond et al., 2011)⁴⁷. The AAQ-II or FFMQ could help to address issues with increased symptom scores due to increased awareness of symptoms. For example awareness of symptoms may increase in parallel with the participant’s ability to experience and begin to accept those symptoms. Indeed Pickut et al. (2015)¹⁹ reported significant increases on the pain dimension of the PDQ39 and the ‘observe’ dimension of the FFMQ which could suggest the increase in pain scores is due to participants becoming more aware of their pain since attending the mindfulness course. In light of the study results and the literature concerning the MAAS and mindfulness outcome measures in general⁴¹, an alternative measure could be considered for future research.

Follow-up questionnaires afforded further information on the participants’ experience of the course. At week 8 in response to the question “Has your experience of living with Parkinson’s changed at all since attending the MBSR course?” one participant selected “Some negative change.” The negative change could refer to the natural worsening of their Parkinson’s symptoms, or they could be more aware of their

symptoms due to being more mindful. The wording of the question is unclear and so renders the response ambiguous. This could be improved for future studies. The same participant also commented that the course was stimulating and worthwhile attending so the 'negative change' they experienced did not give them a negative view of the MBSR course.

At week 16 the reasons reported for not continuing to practice mindfulness were related to personal circumstances and fatigue. For this particular client group it may have been useful to place more emphasis on shorter practices and mindfulness of everyday activities rather than the longer practices. This may be easier for people with Parkinson's to sustain long-term. Indeed there is emerging evidence that shorter formal mindfulness practice, and informal mindfulness practice alone, can be of benefit^{20,48,49,50}.

Thematic analysis of the qualitative responses highlighted the positive and negative aspects of the MBSR course: it was perceived as life-enhancing as well as challenging. Some participants said they benefitted from meeting other people with Parkinson's so our findings could be affected by the social effects of group activity. According to Simpson, Haines, Lekwuwa, Wardle, and Crawford (2006)⁵¹ there is a complex relationship between social support and psychological outcome in people with Parkinson's and "in order to promote well-being, the development and encouragement of activities to improve social network size and quality, and possibly also self-esteem, should also be emphasized." (Simpson et al., 2006, p.589)⁵¹. Future research may wish to consider the use of a non-mindfulness group activity as a comparator in order to determine if the effects of the intervention are due to the social aspects, mindfulness practice, or both.

Although participants gave positive feedback on the course they also reported some difficulties such as finding the time to practice, and some confusion around concepts and the aims of practices. Difficulties in the early stages of a mindfulness course are typical and due in part to the many paradoxes of mindfulness. For example the aim of mindfulness practice is not to bring about change but to notice experience as it is, in a non-judgemental way and if possible with kindness. It is this acceptance and 'non-doing' which paradoxically can lead to change²³. Such concepts can be difficult to understand and require patience from the participant and a skilled mindfulness teacher to guide the participant to understanding⁵². One participant was confused by the use of the word 'sensation' to describe physical feelings. The word sensation is commonly used in mindfulness practice, training and literature, however the participant reported they were expecting to experience something 'sensational' or out of the ordinary and so thought they were not doing the practices properly. Another participant was confused by the mindfulness teacher referring to the feeling of 'feet on the floor' when the teacher's feet were actually on a small block on the floor. Although these were small details which were resolved with the support of the teachers, they initially acted as a barrier to participants effectively engaging in some of the practices, so care should be taken with the language used when running an MBSR course. Some client groups may benefit from explanations and reminders of terminology in the course handouts.

Additional adaptations were made as the MBSR course progressed, for example as a result of difficulties participants experienced when focussing on sensations in the body. The body scan was adapted to include some gentle movement and mild tensing and releasing of the muscles, like progressive muscle relaxation⁵³. This also helped with the tendency for participants to fall asleep during practices longer than 10 minutes as the movement was rousing. Participants responded well to exercises involving external stimuli such as heat pads but struggled with practices without

external stimuli or movement, reporting they could feel very little (if any) sensation in their body. There was concern that continuing with these practices in the standard format could result in prolonged confusion or frustration. Therefore, alternative practices that served the same aims as the original practices were introduced. An example includes inviting the participants to use an object held in their hands as an anchor for their attention while the researcher wheeled a trolley up and down the corridor outside the practice room which generated a range of different noises that increased and decreased in volume. This provided a vivid experience of how the attention was pulled away from the chosen focus for the attention, allowing this to be clearly noticed and also choices then made to redirect the attention back to the chosen focus. The participants experienced a range of reactions – confused thoughts, thoughts about what the noise might be (problem-solving), physical tension or other physical reactions, and emotions such as surprise. The practice was useful as it enabled participants to become aware of the full range of their reactions, including areas in the body where physical tension increased. Konczak, Krawczewski, Tuite, and Maschke (2007)⁵⁴ also found people with Parkinson's experienced difficulties identifying physical sensations. The authors concluded that the ability to perceive passive forearm motion was impaired in patients with Parkinson's. Interestingly, with regard to neglect phenomena in stroke and possibly Huntington's disease, attention plays a role in sensory and visuo-spatial impairment^{55,56}. Furthermore, recent neuroscience research suggests the motor system (which is impaired in patients with Parkinson's) is involved in bodily self-awareness and that movement increases awareness of the body⁵⁷. The current study supports these findings and reinforces the need to adapt the intervention to the needs of participants. Indeed, the decision of the MBSR teachers to introduce gentle movement to the body scan practice appears to be well founded and would be recommended for other patient groups with impairment of the motor system.

The drop-out rate was high with 7 of the 13 participants withdrawing from the study. However the study population was elderly with co-morbidities so there was a risk that ill health could affect continuation on the course. Some of the participants who had been ill or unable to attend due to last-minute work issues asked if they could rejoin the group, but due to the number of sessions missed the MBSR teachers thought those patients would not be able to catch up and they did not wish to disturb the dynamics of the continuing group. So although the drop-out rate was high, the wish of some participants to re-join the course indicates that the intervention could still be viewed as acceptable to patients. A study assessing the effects of MBCT on previously suicidal individuals also had a high drop-out rate. Sixteen participants were recruited and of these, four withdrew before the course began and two withdrew during the course⁵⁸. When designing future studies researchers need to consider potentially high drop-out rates.

This study has a number of strengths and limitations. The qualitative data complements the quantitative data, providing a greater understanding of the participants' experience of the MBSR course and of how the course may have affected their lives. Information regarding course adaptations will be particularly useful for clinicians and practitioners considering providing mindfulness-based interventions for people with Parkinson's.

The findings should be treated with caution as the results were not adjusted to avoid Type 1 errors and the sample size consisted of only six participants. Further research with a larger sample size is required to obtain more robust results. A control group or alternative group intervention could also be considered for future studies.

Future research could include carers in mindfulness courses for people with Parkinson's, as recommended by Cash et al. (2015)²⁰. Some of the participants in

this study were driven to the course venue by carers who had their own health problems and responsibilities. There is evidence that the wellbeing of the informal carer has an impact on the health-related quality of life of the patient and more support interventions for carers are needed^{59,60,61,62}. Carers could also support people with Parkinson's to continue to practice mindfulness, acting as a 'practice partner'.

5. Conclusions

Although this study has a number of limitations the findings support the existing evidence base. The results indicate that mindfulness-based interventions are effective for the treatment of non-motor symptoms in people with Parkinson's disease and are acceptable to patients. The findings also suggest that further adaptations could be made to tailor the intervention more specifically to people with Parkinson's.

In conclusion, this study supports the findings and recommendations from previous studies for the use of mindfulness-based interventions for people with Parkinson's. More robust research including randomised controlled trials and the involvement of carers is required.

Ethical standards: This study was given approval by the University of Salford Research and Governance Ethics Committee (reference: 12/13-10) and the NHS National Research Ethics Service Committee North West – Greater Manchester West (REC reference: 13/NW/0011). The study has therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. Informed consent was obtained from all participants prior to participation in the research.

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