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Full title: Experiences of Mindfulness Training in Living with Rheumatic Disease: An Interpretative Phenomenological Analysis

Running title: IPA, Mindfulness and Rheumatic Disease

This study examined experiences of Mindfulness training for 5 adults living with Rheumatic Disease. Focus group data was used to explore the experience and impact of Mindfulness training in participants aged between 46 and 69 diagnosed with Psoriatic Arthritis, Fibromyalgia or Rheumatoid Arthritis. All participants had completed an 8-week Mindfulness-Based Stress Reduction Programme (MBSR) 6 months prior to the study. Interpretative Phenomenological Analysis produced two themes: 'responding to pain' and 'psychological well-being'. All participants spoke similarly and with enthusiasm, reflecting the strength of the impact of Mindfulness upon the daily lives of these individuals. Methodological limitations are considered along with clinical applications and suggestions for future research. The findings from this study reinforce the outcomes of previous research and indicate that Mindfulness has potential to improve the health and well-being of individuals living with Rheumatic Disease.

Keywords: Rheumatic disease; chronic pain; mindfulness; interpretative phenomenological analysis

Introduction

Rheumatic disease (RD) is characterised by physical, functional, psychological and social impairment (Astin *et al*, 2002). Recently, holistic approaches to RD include ‘acceptance-based’ approaches like Mindfulness, (e.g., Hayes *et al*, 1999), which challenge the traditional dominance of Cognitive-Behavioural Therapy (CBT) (Morley *et al*, 1999). Acceptance-based perspectives promote ‘pain acceptance’, which is associated with positive physical and psychosocial adjustment (McCracken, 1998). This study investigates RD patients’ experiences of Mindfulness training.

Research questions

What are participants’ experiences of Mindfulness in relation to:

- Coping with pain?
- Psychological well-being?

Literature review

Mindfulness has origins in Eastern meditation traditions, but has been incorporated, independently of religious beliefs, into clinical interventions (Baer, 2005) including Mindfulness-Based Stress Reduction (MBSR). A typical MBSR programme involves a day’s training plus 2 hours per week for 8 weeks. Participants are taught non-judgemental observation of sensations, thoughts, emotions and external events (Kabat-Zinn, 1990). Participants are taught to regard their current states as passing events, not all-encompassing and enduring experiences. Increased awareness and acceptance of present experience potentially counteracts habitual avoidance or suppression of difficult sensations and experiences (McCracken *et al*, 2007). Participants also engage in individual and group reflection on observations made during practice, gaining insight into the physical,

emotional and cognitive processes underlying experience (York, 2007). Participants carry out formal practices at home, and are encouraged to practice informally, bringing awareness to routine daily activities (e.g., dressing) (CMRP, 2006). Facilitators generally have an established personal Mindfulness practice.

A number of studies of chronic pain link Mindfulness with improved emotional, social and physical functioning (Kabat-Zinn *et al*, 1985; Dahl *et al*, 2004; Morone *et al*, 2008). These improvements may be related to pain acceptance (McCracken *et al*, 2006) and can last several years (e.g., Miller *et al*, 1995). Furthermore, MBSR provides lasting improvements in psychological well-being and pain-related coping in RD patients (Grossman *et al*, 2007; Pradhan *et al*, 2007). A comparison of depressed and non-depressed RD patients who received either CBT, Mindfulness or Education found Mindfulness especially beneficial for those with chronic depression (Zautra *et al*, 2008).

Such studies show benefits of Mindfulness on physical and psychological health, but focus on quantitative outcomes, especially symptom reduction. This has clinical relevance and value but leaves participants' complex experiences and perspectives unexplored. Qualitative research in adults with RD is needed to illuminate perspectives on the daily application of Mindfulness for pain-related coping.

We therefore used qualitative focus groups, which are useful for eliciting individuals' perspectives (Wilkinson, 2003), especially in relation to 'sensitive' topics where a group context may facilitate disclosure (Frith, 2000). The participants were an established group who, having undergone MBSR together, were already accustomed to disclosure as a group. Qualitative research adds depth to the existing quantitative literature and makes a timely and important contribution to understanding how individuals with RD experience Mindfulness.

As we aimed to explore experience, the data was analysed with Interpretative Phenomenological Analysis (IPA) (Smith, 1996) - an idiographic, qualitative method that explores participants' perspectives. Focus groups for IPA has been recommended when one is confident that participants can discuss personal experiences in sufficient detail within a group. For the reasons explained above, we felt this was the case with this group.

Method

Participants

Participants were all currently under care of a Consultant Rheumatologist, were not awaiting further medical interventions, had a definite rheumatology diagnosis, had completed a hospital-based MBSR Programme and had no significant psychological co-morbidity. They were referred for MBSR due to difficulties coping with pain but had no prior experience of pain management clinics or psychological pain interventions. We contacted 11 individuals who had completed MBSR (as described above plus refresher course after 3 months) in 2007. Six consented but ill-health made this 5. Participant pseudonyms, ages and diagnoses are shown in Table 1.

Table one here

Data Collection and Procedure

The study received ethical approval from University and NHS Ethics Committees (ref 07/H1014/77) and complied with relevant guidelines.

Participant ill-health meant that two separate one-hour focus groups were facilitated by the first author (a colleague observed and assisted with practicalities). A single focus group with five participants was originally planned, but two participants cancelled at short notice. In order not to waste the time of those who had attended it was decided to go ahead with the three participants who had attended and then to hold another group interview with the remaining two at a later date. Flexible, open-ended questions allowed relatively unconstrained interaction. Data was recorded, downloaded onto a password-protected PC and transcribed.

Participants knew the first author as their Occupational Therapist and MBSR course facilitator. She is formally trained in Mindfulness teaching, engages in personal Mindfulness practice and – consistent with good practice - is supervised by a more experienced Mindfulness teacher (CMRP, 2006). The first author facilitated the focus groups because she has existing rapport with the group and has the relevant skills and experience to facilitate discussion on this specialist topic.

Data Analysis

Data was analysed with IPA (Smith and Osborn, 2003): Transcripts were read repeatedly to gain understanding of each participant's account but also, as focus groups were used, attention was paid to group interactions (recommended by Smith, 2004). This reading of transcripts and preliminary coding formed the basis for more abstracted emergent themes. Further cross-case analysis resulted in a table of themes that captured most strongly the participants' experiences. It was then necessary to exclude some themes to keep the findings focused. As recommended by Smith *et al* (1999), themes lacking richness or not illuminating other themes well were omitted.

A number of steps were taken to ensure a rigorous analysis. A thorough and systematic analysis that follows established guidance is needed to avoid, amongst other things, the danger of anecdotalism - where the finished analysis is only consistent with part of the data set and is supported by selective examples rather than a thorough analysis of all data in the set (Silverman, 2005). To this end, initial coding was done 'line by line', analysis was done by both authors and compared, analytic procedures were guided by the principles of constant comparison and refutability (that is, a conscious effort to seek out data that disconfirms growing interpretations and explanations during analysis) and divergent cases were analysed and are presented in the written analysis (see Lorna's account of 'directing attention' [below] for an example of this) (Silverman, 2005; Yardley, 2008).

Findings

Two clinically relevant themes emerged in relation to the aims - 'responding to pain' and 'improved psychological well-being'.

Responding to pain

A common theme, unsurprisingly, was the experience of pain, its meaning and responses to it. Participants' descriptions emphasised how, before Mindfulness, pain was overwhelming and debilitating, dominating life and reducing well-being.

Lindsey describes her pain, pre-MBSR, as '*dreadful, debilitating and depressing ... [it] ... stopped me from doing ... things*'. Similarly, Jacky described her pain before the Mindfulness course as '*there all the time*', making her '*frightened of trying things .. [and] ... in despair*'. Pain's was often represented as causing despair and depression (this is explored further in 'psychological well-being').

Participants described how applying Mindfulness techniques allowed more responsive approaches to pain – e.g., deliberately engaging with the experience. Rachel describes using Mindfulness to *‘find out where the pain is.... breaking it up.... slowing down into [it]’*. This awareness and exploration allowed Lindsey to *‘now rest into the pain rather than trying to battle through it’*.

These descriptions clearly reflect some of the attitudes and skills taught in MBSR – e.g., participants are taught to deliberately direct awareness from one aspect of experience to another (CMRP, 2006). It is anticipated that choosing to deliberately focus attention on current experiences, when safe to do so, will eventually replace the experience of feeling overwhelmed by painful experiences that seem beyond one’s control. Consistent with this, participants saw themselves as becoming more aware of their choices about how to respond to pain, resulting in more conscious decision-making. Lorna described applying the skill of ‘re-directing attention’ to pain experienced during daily activities:

*‘You could be stood ... trying to peel your potatoes [with] ... terrible pain ...
and you can decide to put your attention on something else’.*

It is unclear, however, whether Lorna’s description reflects the application of this Mindfulness skill or a method of distraction and avoidance. Directing and redirecting attention is taught so as to develop the skill of deliberately focusing on present moment experiences, not to develop ways to avoid them. This distinction is crucial yet subtle as Lorna’s account illustrates. She may have learned to re-direct her attention, continuing to use it as means of dealing with pain through avoidance, without developing the further skill of staying with the present. Or she may have chosen, on this occasion, not to use her skill to stay with the present. The available data do not allow us to

determine this, but do illustrate that the distinction between re-directing attention and avoidance can be particularly subtle for participants.

Each participant reported favourable outcomes from Mindfulness. Rachel reported '*the pain is actually less*'. Lorna felt that, with the use of Mindfulness, '*the pain isn't as bad ... re-directing your attention definitely works*'. In terms of how participants apply Mindfulness to cope with pain, the data clearly illustrates a process of moving from pain reactivity, e.g., '*you get worked up*' (Jacky) towards responding to pain, e.g., '*I rest into the pain*' (Lindsey). Even '*re-directing your attention*' (Lorna) can be considered responsive because it reflects conscious decision-making about handling the pain experience.

There are several possible explanations of how these effects of Mindfulness occur. These findings are consistent with Kabat-Zinn's (1982, p. 35) view that pain reduction results from '*an attitude of detached observation toward sensation*'. Repeated Mindfulness practice may uncouple the sensory component of pain from the affective and cognitive dimensions, resulting in a specific de-conditioning of reactivity, as consistent with gate control theory (Melzack and Wall, 1965). Also, Baer (2003) suggests that Mindfulness may be beneficial in chronic pain by prolonging exposure to the sensations of pain (through deliberate attention) in the absence of catastrophic consequences, which in turn may lead to desensitization. Over time, and with practice, Mindfulness may allow individuals to experience pain with reduced emotional reactivity. Determining which, if any, of these explanations is most useful is beyond the scope of this study, but our findings suggest that this deserves attention.

Psychological Well-being

Participants consistently said that living with RD, and in particular pain, affects their mood. For example, pain *'makes you ratty'* (Lorna) and is *'depressing'* (Lindsey).

Two participants in particular reported depressive experiences associated with chronic pain and physical limitations. In describing the impact of RD on her mood, Lesley stated that *'one of the things that depressed me the most at the start was ... I was so ... tired and ... sore ... I had to give up my job I was very, very depressed about that'*.

John's experience was similar:

'Depression is a big thing ... and it does cost you a lot when you lose your job ... you want to be like the chap next door, ... but you can't, that's when you get depressed. When the pain is bad it can make you depressed and sometimes the depression is as bad as the pain'.

Both Lindsey and John reported that applying Mindfulness meant less depression, more acceptance of their condition, more appreciation of life and a greater sense of well-being. Reflecting upon her more recent experience Lindsey states that she is *'coming to more of an acceptance and ... the course has helped ... like appreciating what I have* In response to this, John states that he is now more *'calm and accepting'* because of the Mindfulness training:

'[With the Mindfulness] meditation...I haven't been as depressed for a long while. You ... notice that your mood is slipping and then I decide to ... give time to this [meditation practice], rather than getting caught up in 'I can't do this and that', 'cos once you start getting low you can get dragged down more.'

John's comments support previous findings that Mindfulness can be effective for depression by training people to recognise 'relapse signatures' and use Mindfulness skills to prevent the triggering of habitual negative thought patterns (Segal *et al*, 2002). That John developed this skill during an MBSR programme provides support for Mindfulness as a therapeutic tool. Furthermore, John's account reveals that he is consciously deciding in response to depressive symptoms, supporting the view that Mindfulness facilitates the recognition of choices and responsiveness.

Participants also commonly reported improved well-being in relation to appreciation of their surroundings and attitude to life. For example, Jacky described being *'in the garden listening to the birds.... really enjoying nature and life'*. This greater awareness of the immediate environment is also reflected in Lindsey's account:

'I've always enjoyed nature but now I'm noticing more, like watching the seasons change. ... There is a Hawthorn bush and I've noticed how it's changed, when it's in blossom ... and I get a sense of peace and well-being from it, more so than ... before'.

Participants also commented that family and friends had noticed positive changes in their behaviour and mood. For example, Rachel says *'I feel better, you know, and people have said that – 'you're smiling more'*.

There is evidence here of a shift from low mood or depression towards a more positive affect and greater psychological well-being and participants clearly attributed this change to Mindfulness. When asked whether they had experienced any negative effects or difficulties in using Mindfulness, all participants stated that, overall, they had not – although some of them did comment that they found the longer practices to be challenging because of their relatively time consuming nature. Lindsey, for example, said that she had *'found the body scan difficult 'cos it is quite long'*.

These findings are also consistent with earlier research in which Mindfulness has been associated with lasting improvements in psychological status in chronic pain patients (Kabat-Zinn *et al*, 1987; Morone *et al*, 2008) and rheumatoid arthritis (Pradhan *et al*, 2007). It is possible that the emotional regulation aspects of Mindfulness could be responsible for such effects (Zautra *et al*, 2008).

General Discussion

A more general discussion follows, noting key findings, limitations and clinical applications.

Key findings

Participants consistently described using Mindfulness practices and experience this as helpful in relation to pain, activity tolerance and psychological distress. There is an on-going commitment to Mindfulness practice amongst these participants, highlighting its potential to become integral to daily life, with benefits maintained over time.

Methodological Limitations

Participants reported a number of benefits to their health and well-being but limitations must be considered. One key issue relates to the use of focus groups.

Although participants spoke relatively freely in the focus groups, examining individual cases in detail is central to IPA. At times, the group setting may have hindered the exploration of individual experience in detail. For example, when Lorna talked about the application of re-directing attention (above), it was not clear whether she was using this in a way that is consistent with Mindfulness or, rather, as a means of avoidance. In the group context it was less easy to pick up on this point and explore it further with Lorna, so the opportunity to gain insight into what is happening here was missed. This is an important consideration for the development of focus groups in IPA.

Furthermore, it should be born in mind that these focus groups consisted of fewer individuals than generally recommended in the focus group literature. It is possible that this may have reduced the degree of group interaction within the interviews. The small sample size also means that caution should be exercised in attempting to generalise beyond these participants.

Another issue is the role of the first author as researcher and clinician and the potential impact of this on the research. Within IPA, the researcher is the primary analytical instrument and their beliefs are seen, not as biases, but as necessary for making sense of others' experiences (Smith, *et al* 1999). This is consistent with a 'constructivist view' that sees researchers as central to constructing research findings – a view that is well established within qualitative research (Madill *et al*, 2000). Engaging in personal Mindfulness practice potentially gives the researcher an insider perspective

that aids understanding. According to the principles of reflexive research, we view all researchers as potentially influencing the research process but consider the appropriate response to this to be openness about the roles and standpoints of the research team, rather than adhering to the belief that adopting a particular method, or particular researchers, will remove subjectivity entirely from the research process (Yardley, 2008).

Although it is important to bear in mind the consequences of the small sample size, ~~The~~ this small qualitative sample provided detailed accounts and allowed participants to raise issues, ~~but caution is needed in generalising~~. The participants were mostly women, raising questions about the extent to which men's experiences are captured. RD is more prevalent in females (Hammond and Jefferson, 2002), so this is commonly reflected in the gender ratio of samples, and the Mindfulness literature reveals little evidence of systematic gender differences. Nevertheless, accounts of men's experiences of Mindfulness would extend these findings.

All participants spoke similarly and positively, suggesting that Mindfulness has a strong and beneficial impact upon these individuals. The nature of the study, however, does not illuminate whether this would be case for all patients undertaking MBSR. The first author's clinical experience indicates that at times some individuals struggle to practise Mindfulness. However, in this study, as in others, there are few accounts from individuals who found Mindfulness training difficult or ineffective (perhaps because they are less likely to volunteer) and so this is left unexplored.

Clinical Applications and Future Directions

This study has shown that Mindfulness practices can be incorporated in a relatively lasting way into the lives of some patients with RD and this has particular clinical relevance. Although in some instances psychological interventions only show short-term benefits (Kraaimaat *et al*, 1995), the findings of this study are consistent with previous evidence of longer-term benefits with acceptance-based approaches (e.g., Pradhan *et al*, 2007).

Research suggests that Mindfulness may be more effective when on-going support mechanisms are in place (Pradhan *et al*, 2007) but questions remain about what specific factors are involved. Furthermore, to identify when and for whom Mindfulness is suitable, and when it is contra-indicated, future research should obtain perspectives from those who have struggled with Mindfulness.

Conclusions

This first qualitative study exploring experiences of Mindfulness in individuals with RD, demonstrates that Mindfulness improves psychological functioning and well-being for some patients, although caution is needed in generalising. For clinicians, the potential of Mindfulness as an effective adjunct to the medical management of RD is highlighted.

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Table 1: Participant ages and primary rheumatology diagnoses

Pseudonym	<u>Group</u>	Age	Diagnosis
Rachel	<u>1</u>	46	Psoriatic Arthritis
Jacky	<u>1</u>	55	Fibromyalgia
Lorna	<u>1</u>	57	Rheumatoid Arthritis
Lesley	<u>2</u>	63	Rheumatoid Arthritis
John	<u>2</u>	69	Rheumatoid Arthritis