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# "I'm empowered to look after myself" - Mindfulness as a way to manage chronic pain: an interpretative phenomenological analysis of participant experiences in Scotland

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#### Abstract

#### Background

Chronic pain is a common problem that can impact on psychological and social wellbeing and activity levels. Despite pharmacological treatments, there is often a lack of improvement in physical and emotional functioning and health-related quality of life. Mindfulness meditation has become an increasingly popular self-management technique.

#### Aim

The aim of the study was to explore the experiences of patients with chronic pain who took part in a mindfulness programme.

#### Methods

A mixed-methods feasibility study was carried out. Participants were aged 18 years or over with non-malignant chronic pain recruited from general medical practices in Fort William, Scotland. In 2013 participants undertook an eight-week mindfulness programme based on Mindfulness-Based Stress Reduction (MBSR) and were interviewed immediately postprogramme and at eight-months post-programme. Analysis of qualitative data involved Interpretative Phenomenological Analysis (IPA).

#### **Findings**

Thirty-four patients consented to take part in the study; twenty-four took part in the programme (14 attended four or more sessions, 10 attended one to three). Twenty-three were interviewed. Participant experiences of the programme were themed under: factors affecting experience (influence of earlier life events; the process of taking part in, and of relating to, the programme); and effects of the programme (impact on emotions, mental health, adverse events and a process of change). The process of change, resulting after better understanding

the relationship between mindfulness and pain, involved learning to 'listen to the body', gaining a sense of community, learning to accept pain, and approaching life with more self-care, awareness, appreciation and empowerment.

#### Conclusion

Participants reported a variety of experiences. For some, these included undergoing a process of change which may have supported them in living with their painful condition. This contributes to our understanding of how mindfulness could benefit people with chronic pain.

#### Keywords

Chronic Pain; mindfulness; Mindfulness-Based Stress Reduction; interpretative phenomenological analysis; participant experiences; pain management; process of change; pain coping

#### Highlights

- Earlier difficulties influenced participant experience of the mindfulness programme
- Unfulfilled expectations around pain control led to drop out
- Understanding the relationship between mindfulness and pain was key to engagement
- Programme experience involved transitioning to pain acceptance and empowerment

#### 1. Introduction

Chronic pain, defined as pain that lasts or recurs for more than three to six months (Dahlhamer *et al.*, 2018; Fayaz *et al.*, 2016), is a common problem with a prevalence varying from 20.4% (USA) (Dahlhamer *et al.*, 2018) to 43.5% (UK) (Fayaz *et al.*, 2016). These differences could be attributed to variations in study inclusion criteria, pain measures used, sociodemographic and healthcare variations in different study populations. Chronic pain can impact physical and psychological health (Fine, 2011), social wellbeing (Breivik *et al.*, 2006), activity levels (Parker *et al.*, 2017) and employment (Breivik *et al.*, 2006). Despite pharmacological treatments, there is often little improvement in physical and emotional functioning and overall health-related quality of life (Martin *et al.*, 2008). Other treatments are needed that address the multifactorial nature of chronic pain (Turk, Wilson and Cahana, 2011). Rather than aiming to eliminate the physical pain, non-pharmacological approaches often emphasise coping, self-management and adaptation (Turk and Gatchel, 2018).

Mindfulness meditation has become increasingly popular for self-management of many long-term conditions, including chronic pain (Mars and Abbey, 2010). A widely accepted definition of mindfulness is '*paying attention in a particular way: on purpose, in the present moment and non-judgementally*' (Kabat-Zinn, 1990). This 'paying attention' is described as occurring with a quality of affection and compassion (Kabat-Zinn, 2003). The most frequently cited method of mindfulness training is the Mindfulness-Based Stress Reduction programme (MBSR) (Kabat-Zinn, 2003) involving the following core components: sitting meditation; body scan meditation; mindful movement; and daily home practice (Crane *et al.*, 2017; Santorelli *et al.*, 2017). The primary aims of mindfulness are not to change the symptoms (although this may occur) (McCracken, Gauntlett-Gilbert and Vowles, 2007) or control the internal experience (Crane *et al.*, 2017) but to enable a person to relate differently to their experience (Crane *et al.*, 2017) and cope better with their symptoms (McCracken, Gauntlett-Gilbert and Vowles, 2007). This could be of value in the context of a multifactorial chronic illness such as chronic pain.

A number of systematic reviews looking at the effects of mindfulness for people with chronic pain have been conducted recently, finding significant improvements in depression symptoms (Ball et al., 2017; Hilton et al., 2017) and health-related quality of life (Hilton et al., 2017), and some improvements in pain symptoms (Anheyer et al., 2017; Bawa et al., 2015; Hilton et al., 2017). Some theoretical models have been suggested proposing how mindfulness programmes may work in a general population, such as the Attention, Intention and Attitude model (Shapiro et al., 2006), and in a chronic pain population, such as the Mindfulness Framework for Chronic Pain (Day et al., 2014) and the psychological flexibility model (Harrison et al., 2017). Adapting to having a chronic pain condition may involve acceptance (McCracken and Eccleston, 2003), which may mediate the effects of mindfulness programmes, although meta-analyses of effects on pain acceptance have shown variable results (Anheyer et al., 2017; Ball et al., 2017; Bawa et al., 2015). Other studies have suggested pain catastrophising (Day et al., 2020), pain management self-efficacy (Wright and Schutte, 2014) and perceived pain control (Day et al., 2020) as mediating factors, indicating that the process is likely to be complex and multi-factorial. Recent qualitative studies describe mindfulness as a facilitator of transition to living with long-term conditions (Long et al., 2016) including chronic pain (Luiggi-Hernandez et al., 2018). The way that mindfulness may enable this transition is not well understood.

As there is currently no consensus on which theory truly represents the processes involved, rather than beginning with an existing model and mapping findings onto that, we chose to conduct an exploratory study using interpretative phenomenological analysis (IPA), that would aim to understand participant experiences. The findings will be compared with previous studies in the field and new insights will be identified.

#### 2. Aim

The aim of the study was to explore the experiences of patients with chronic pain who had taken part in a mindfulness programme.

#### 3. Ethical Approval

Ethical approval was received from National Research Ethics Service (NRES) North of Scotland (REC reference number 13/NS/0011) and from NHS Highland Research, Development and Innovation.

#### 4. Method

#### 4.1 Study design

As part of a mixed-methods feasibility study of delivering a mindfulness programme for patients with chronic pain (reference to 1<sup>st</sup> author's PhD), the experiences of those taking part were explored through in-depth face-to-face post-programme interviews, eight month follow-up telephone interviews, and IPA (Smith, Larkin and Flowers, 2009). A previously validated approach for identifying patients with chronic pain from general practice prescribing records, was used (McDermott *et al.*, 2006).

#### 4.2 Participants

Participants were selected from two general medical practices in Fort William (a town in Scotland with population size 10,500). Those eligible were: aged 18 years or above with non-malignant chronic pain of at least three months duration, receiving

regular prescribed medication for pain; able to read and speak English fluently. Exclusion criteria were: having a concurrent major psychiatric illness; diagnosis of personality disorder; acutely at risk of physical harm to self or others; current known alcohol or drug addiction; pain caused by malignancy; signs of serious underlying illness such as recent unexplained weight loss, fever, or sudden worsening of back pain; medical instability from heart or lung disease or other severe chronic medical conditions judged by the clinician to place the patient at risk of possible severe consequences of his/her disease; multiple recent falls or inability to stand independently; unable to give informed consent; illiteracy, as they would not be able to complete the meditation diary; serious hearing or vision impairment precluding responding to questionnaires or participating in the meditation program; cognitive impairment.

Identified patients (756) were screened by general practitioners (GPs) from each practice for eligibility and 481 (64%) were mailed a study information pack by the NHS Research Scotland Primary Care Research Network staff (see Figure 1). The target sample size, of approximately 30, was based on the maximum number of participants for a standard MBSR programme (Kabat-Zinn, 2003).

#### 4.3. Mindfulness programme

The essential core programme components, detailed above (body scan, sitting meditation and mindful movement, and daily home practice) were delivered by course instructors who presented topics weekly for eight weeks following the Mindfulness Scotland workbook (Procter and Wilson, 2008). This workbook is based on the standard eight-week MBSR programme delivering the MBSR curriculum (Crane *et al.*, 2017; Kabat-Zinn, 1990; Santorelli *et al.*, 2017). It was given to participants in the form of weekly handouts, supporting adherence to the standard programme. (See online Appendix 1 for summary of weekly topics and online Appendix 3 for the Mindfulness Scotland workbook). Home practice involved guided meditation practices from CDs and written material from the workbook (Santorelli *et al.*, 2017). The programme ran from October 2013 and was led jointly by two NHS clinical psychologists (initials). (Instructor 1 initials) was a mindfulness teacher trainer; both were certified MBSR instructors working within NHS Highland. The first author (initials) met with (instructor 1 initials) four times (before, during and after the programme) to check that the programme delivery was in accordance with the workbook, and discuss any challenges that had arisen. The pre-programme interviews, an integral part of MBSR programmes (Kabat-Zinn, 2014), were conducted by (instructor 1 initials) and included a description of the programme and an opportunity to ask questions. Written consent to take part in the study was taken at this interview. Completion of the mindfulness programme was defined as attending a minimum of four group sessions (based on previous studies) (Bawa *et al.*, 2015; Morone *et al.*, 2009; Schmidt *et al.*, 2011; Sephton *et al.*, 2007; Weissbecker *et al.*, 2002).

#### 4.4. Data collection

A semi-structured interview topic guide, using an IPA approach (online Appendix 2) was developed based on the literature (Biggerstaff and Thompson, 2008; Smith, Larkin and Flowers, 2009). Interviews were conducted immediately post-programme (December 2013) and at eight months post-programme (August 2014) by the first author (initials), who is a GP and mindfulness practitioner, and were audio-recorded and transcribed verbatim.

#### 4.5. Data management and analysis

Data were stored using NVivo version 10 software and analysed using IPA (Smith, Larkin and Flowers, 2009). Coding was led by the first author (initials). This included listening to the recorded interview and repeated reading of a participant's transcript to enable deeper understanding of their experience prior to coding the data and initial identification of emergent themes. This was repeated for each participant. Trustworthiness (Lincoln and Guba, 1985) of the data was assessed by independent in-depth coding of one transcript by (initials), an experienced IPA researcher, with areas of disagreement resolved by discussion, leading to further refinement of themes and their underlying meanings (O'Connor and Joffe, 2020). Iterative reviewing of these themes jointly by these two authors (initials) informed subsequent coding and theming (Tufford and Newman, 2012). Themes relevant to participant experiences of the programme were selected and arranged into clusters of related themes. Since greater depth of IPA analysis is facilitated by smaller sample sizes (Smith, Larkin and Flowers, 2009), the data was separated into completer and non-completer subgroups for analysis. This also allowed exploration of the hypothesis that experiences may differ according to completer status.

#### 4.6. Reporting of findings

The narrative of the findings reports themes relevant to participant experiences (see Table 1). Where there were differences between the experiences of completers and non-completers, this is stated. Verbatim quotes are given, selected on the basis of richness in illustrating a theme, presented individually or linked together where they describe an experience over time (Biggerstaff and Thompson, 2008). Quotes are identified by participant ID, status (completer, or non-completer) and data source (D1: post-programme interview, D2: eight-month follow-up interview). Modulation of the speaker's voice is indicated by square brackets before the word or phrase, capitals used for emphasis, [....] for text removed and XXX where a word is omitted for confidentiality.

#### 5. Findings

#### 5.1. Recruitment and retention

The details of recruitment and retention are shown in Figure 1. Twenty-three participants attended a post-programme interview and 22 attended eight-month follow-up.

Figure 1 to appear here

#### 5.2. Study population characteristics

Of the 23 participants who attended a post-programme interview, the majority were: aged 50-65 years (15/23), female (20/23), white Scottish (16/23), and Christian (17/23). O-level/A-level/diploma/GCSE was their highest educational qualification (12/23), and nearly a third were retired (7/23). The most common pain condition was osteoarthritis (10/23).

#### 5.3. Participant experiences

Participant experiences of the programme varied greatly. They are presented under two broad categories: factors influencing experience and effects. Under each category, clusters and sub-clusters of related themes are presented. These are illustrated in Figure 2 and described below.

#### Figure 2 to appear here

Most themes grouped within each cluster were reported by both completers and noncompleters. Some themes (such as those under 'process of change') were mostly reported by completers, and a few themes were exclusively reported by completers or non-completers as illustrated in Table 1 below. Table 1 to appear here

#### 5.3.1. Category 1: Factors influencing experience of the programme

#### 5.3.1.1. Earlier life experiences

Some participants described previous difficulties, such as being excluded due to disability or being disbelieved about being in pain, that may have influenced how they experienced the programme. One non-completer described feeling hurt in the past by being excluded from group activities due to disability. She dropped out after the first session,

'Oh, that was a long while ago [....] it hurts me, they don't seem to understand how much it hurts me, you know, not being able to do it, [....] watching everybody else enjoying themselves, and I'm just sitting there like an idiot.' (G74, non-completer, D1)

Another non-completer described feeling disbelieved by his mother who didn't appreciate that myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a recognised medical condition,

'My mum on the phone, she's like, "'So, so what's wrong this time?" I said, "Well, it's the same as last time, I told you, I've got this ME type thing." "Oh, right" [quieter speech starts] she lives in a village [quieter speech ends], "Oh right, so and so says they've got that" and it's always a different so and so. And it's always not that they've got it, it's "So and so <u>'</u>SAYS' they've got that", and you can hear the wheels going, [quieter speech starts] "Is so and so a bit of a nutter?" [quieter speech ends], and it's like, I just thought, "God almighty, WHY AM I HAVING TO EXPLAIN THIS EVERY TIME?"' (G59, non-completer, D1)

He described being offered an antidepressant (fluoxetine) when he went to his GP with pain,

and expressed that the programme being run by psychologists implied a perception that pain

is all in the mind. He dropped out after the 2<sup>nd</sup> session.

'Going in with complaints that GPs can't deal with and it's more convenient for the GPs to write it off as psychological [....] and then to go into a mindfulness class and be confronted with a psychologist, you think, "[quieter speech starts] Right here we go again [quieter speech ends], it's 'pain is all in the mind' nonsense"[....] and so I'm communicating with LOTS of people, I think there's 250,000 in this country, registered, um, who are all in the same situation, have ALL been disbelieved, more or less all been disbelieved by their GP.' (G59, non-completer, D1)

#### 5.3.1.2 Process of taking part

For some, disability limited their ability to participate. One non-completer described difficulty sitting, standing and walking during the programme, causing feelings of discomfort which may have led to her dropping out,

'The sitting, I'm not very good at. [....] I've to get up and move, because I can't get comfortable, and I'm starting to slide down the chair [....]. But that was the only thing, the sitting, standing, walking, that's my bad points.' (G74, non-completer, D1)

Balancing the need to care for others with caring for oneself was sometimes a challenge. Some expressed guilt around taking time for themselves to do the practices. One completer gained insight into her need for self-care, realising that she is entitled to take space and time for herself.

'I think the biggest insight for me, for the whole thing, was suddenly thinking, "Actually I am entitled to have this space, I NEED THIS TIME AND SPACE [slower speech starts] TO COPE WITH [slower speech ends] THE REST OF MY LIFE, to manage other things."' (G21, completer, D1)

#### 5.3.1.3. Relating to the programme

Several participants began the programme with expectations of pain relief. When the first session did not focus explicitly on pain control, the majority doubted whether the programme would benefit them, causing some to drop out. For many, it took time to understand the objective of the programme and its relationship to pain. This understanding seemed to occur around week four, predominantly among completers who started engaging more with, and finding benefit from, the programme. One non-completer expressed that she did not understand the purpose of some exercises, such as eating a raisin mindfully, and that an explanation may have encouraged her to continue with the programme,

'The two weeks I was there [....] you know how you feel a bit stupid, about different things, the raisins and all, they were asking us to do them and um, mindfully, but they

[Slower speech starts] weren't saying why. [Slower speech ends] [....] In my head I kept thinking [quieter speech starts] "Why? [quieter speech ends] Why are we doing this? Why are we doing this?" [....] Even if it didn't connect maybe with the pain side of it at the time, if she'd still, maybe explained exactly WHY we were doing this, maybe it would have encouraged me to keep going. [....] I just felt no connection with it, at all, [....] I don't feel it was for me.' (T194, non-completer, D1)

One completer described how she was initially resistant to the connection between

thoughts and pain, however later learned to understand this connection,

'I was very resistant to it before. [....] I used to see it as that, as the pain, whereas that's just a whole part of it, and it is about my head, it is about my thinking, it is about how I'm reacting to it, it is about accepting it, if that makes sense.' (G50, completer, D1)

#### 5.3.2. Category 2: Effects of the programme

#### 5.3.2.1. Impact on emotions

The experience of pain and disability brought on difficult emotions such as anger and

frustration, and some participants had additional difficulties. Mindfulness practices helped to

manage these. For example, one completer voiced annoyance at not finding a solution to ease

his pain, and difficulty dealing with his health conditions,

'[Slower speech starts] *I feel* [pause 2 seconds] *ANNOYED that I'm in this situation with my health.* [pause 2 seconds] *I feel annoyed that* [pause 1 second] *there hasn't been any ANSWER to specifically help me.* [slower speech ends] *I feel annoyed that I can't take a pill and it will go away, and stay away, and I can't keep taking the pill, I feel REALLY annoyed at that [....] and I sometimes say to myself, "Why,[....] why have I got ALL THESE THINGS, that I'm having to deal with, and live with?"[....] And then something outside of those, comes along [....], the cup's running pretty well near the top a lot of the time [laughs], and I think that that last thing just takes it over the top.' (G87, completer, D1)* 

He described how learning to focus on something within or around him has helped him to

manage his anger,

I'm trying to sort of, if you like, focus on, on something within me [....], being aware of what's going on, I mean, and just sort of thinking, you know, "What's going on around me?" [....] Those sorts of things have come from the mindfulness, [....] being able to take that a little bit at a time allows me to, if you like, take the pot off the boil, and let it cool down, ready for it to start heating up again, um, in between times.' (G87, completer, D1) One non-completer described how the programme helped her cope better with grief for

her late husband and daughter, bringing her a sense of peace,

'Two years in January since he died, and I feel, since I went to those two (mindfulness programme sessions), er, I'm doing these body scans, and the breathing, and just [Slower speech starts] sitting quietly, I'm back, well probably better than it's been for many, many years [....]. "What if, what if XXXX [daughter] hadn't have died, what if XXXX [husband] hadn't have died", er, "My life would have been different", I've been through all those stages, even to "Why did you leave me", which I know are all the normal, normal processes, he didn't want to go. Er, and since I've listened to the CD, and sat quietly, er emptied my mind, I now feel [Slower speech ends], on a 24-hour basis, I have a much more peaceful mind [....] it's like putting things in the attic. I can keep it in the box now.' (T318, non-completer, D1)

#### 5.3.2.2. Impact on mental health

For some, the emotions associated with chronic pain were particularly significant,

presenting as mental illness such as depression or anxiety; mindfulness was helpful in

managing these. One completer described how a three-minute practice helped her manage

symptoms of depression,

'I got to the stage where I couldn't focus, I couldn't um, I had no concentration, um, I wouldn't remember what I was doing, I wouldn't remember, I wasn't particularly upset, but just numb, just I couldn't really complete tasks, couldn't do anything [....]. I found it quite difficult to come out, to get out anyway, to sort of, I still do. But that's where I find some of this is just, you know, there's that three-minute breathing space, it's just the most, it's wonderful, you know, you just nip into the loo and sit and, you know, and do it and then come out, you're more composed and um, so yes it's benefitted me both, you know, in terms of my pain and you know, the ongoing um, or improving mental condition as well.' (G47, completer, D1)

At eight-month follow-up, one non-completer who continued to practice at home,

described mindfulness helping her sleep difficulties through calming her body and mind,

'Mostly I would do it at night time, because I think it calms, it calms the body and calms the mind, um, and I think if you can, if you can do that before you sleep, you sleep better, and you wake up a bit more refreshed, and ready to go the next morning.' (T233, non-completer, D2)

One participant described having had suicidal thoughts and how the programme had impacted on her ability to manage and recognise what she needed in life to feel fulfilled,

'I really did a very thorough examination of how um, I could do it, I mean it's actually quite easy here, it's hypothermia is the best way. [....] It made me start being um, present, in the present, and the minute the chattering stopped from the past, and it stopped from the front, I could see where, what I needed to do [....] I could see that maybe I could go back to managing it all again. [....] I really had, was lost, completely lost. I think I need these things [....] to feel really fulfilled and satisfied, and, and happy. I need to see colour, I need to feel it, [....] I need to hear it in music, and I need human contact, I need touch and hugs and, so I would say the mindfulness has put that back in place [....] I do much more smiling, I do much more laughing, I can't believe it's that, it was there all along, just can't, [crying] sometimes it's too overwhelming.' (T264, completer, D1)

#### 5.3.2.3. Adverse events

Some reported uncomfortable symptoms during practices. One completer had occasional dizziness during sitting meditation, one was sometimes more aware of his tinnitus, one felt faint on one occasion, one had a sense of panic during a breathing meditation practice, and mindful walking brought on chest pain on one occasion for one participant with a history of angina. Some non-completers reported increased tiredness and pain after the group sessions that may have led them to drop out. One completer found the body scan meditation made his pain worse by making him more aware of it,

'The body scans [Faster speech starts] which I found very difficult on my own [Faster speech ends] [....] I've got used to, if you like, putting it to one side, and dealing with it, it was bringing it to the front again, and in a way, making it worse, I know this sounds silly, making it worse, [Inhalation] um, so I've had a lot more trouble with it.' (G87, completer, D1)

#### 5.3.2.4. Process of change

Those who continued to practice mindfulness beyond the first few weeks (programme completers and a few non-completers who continued to practice at home), and developed an understanding of the relationship between mindfulness and pain, went through a process of change, which comprised of four sub-clusters: learning to 'listen to the body' and learning to accept pain; developing greater self-awareness and empowerment; a sense of community;

and appreciation of life and impact on their spirituality. These sub-clusters are described below.

#### Listening to the body and learning to accept pain

Some participants coped with their pain through distraction and 'pushing through' but this led to suffering. The programme suggested an alternative approach, inviting them to 'listen to their body' (be aware of body sensations and turn their attention towards the pain). One completer described previously pushing through pain which exacerbated it, and now being more accepting of her pain,

'Now I think, "You are sore, you have got pain, that's okay!" Um, whereas before I probably exacerbated the pain, by trying to work through it and pushing myself further than I should have been doing [....], I would come to a complete stand still.' (G50, completer, D1)

She described a more flexible and responsive approach to pain since doing the programme, taking a painkiller or slowing down if needed, rather than avoiding activities due to fear of pain,

'I do come back to, "Well this is how I'm feeling just now", you know, rather than, "Oh god, I was going to do something tonight, but I can't do that, because I'm too sore" [....] so it's, "Well I am sore just now", it's either sore enough to take another pain killer, or you know, maybe just not move about as much [....]. "I'll wait and see what I feel like then", rather than thinking I was going to be sore, you know, I might not be, or I might not be as sore.' (G50, completer, D1)

She described how having reduced tension through taking part in the programme reduced the

intensity of her pain,

'I'm not as tense as I was, which means I'm maybe not as sore as I was [....] so, it's more about how the pain was in my head, although I didn't really think I had much of a pain in my head! [laughs]' (G50, completer, D1)

At eight-month follow-up, another completer described changes to her lifestyle,

including taking life more slowly and stopping when tired, to manage her energy and pain.

'Resting a lot, doing yoga, and walking the dog, walking and just learning to take things more slowly, and more steadily, and when I'm tired, I need to stop and rest [....]. Then you can manage, my energy levels and my pain levels better. I honestly don't, although I might not be doing sort of set exercises, I honestly think that I wouldn't have been able to do those things if I hadn't done the, the course.' (G21, completer, D2)

Developing self-awareness and empowerment

Some participants also developed increased self-awareness, leading to taking greater

responsibility for their feelings and health. One completer realised that she was frequently on

'automatic pilot', shutting off her feelings. Now she was more aware of what she was

thinking and feeling,

'I realised after the first couple of weeks [....], came to an awful realisation that I used to do so much on automatic pilot [....], this capacity that I had to bat it out of my head if I felt sore, so if I wasn't accepting that part, then it kind of permeated everything else [....]. You can't have your brain shutting off from one thing, without it kind of automatically shutting off from other things, so I think that's been a change. [....] I became so much more aware of what I was thinking, how I was feeling [....], I really hadn't thought about them, until I had been doing the mindfulness, because whilst I reflect on everything else, I probably hadn't been reflecting on me.' (G50, completer, D1)

Another completer described no longer blaming others, and being empowered to look

after herself,

'I had to moan a lot, and the more I moaned the worse I'd become, so the, the course stopped all that, [sigh] and it was a breath of fresh air from that point of view, because I could then stop blaming people for not doing things and I could start seeing if those um, there was something I could do for myself [....]. And I've actually been able to focus more and I'm actually getting things done now. I've decided I have to take more on board, so I'm empowered to look after myself more.' (T264, completer, D1)

The sense of empowerment remained at eight-month follow-up,

'I've been quite positive um, and part of me, what happens with that, is that one becomes more empowered to see what maybe you need. I've certainly been able to ask, and be more straightforward about what I needed.' (T264, completer, D2)

#### Sense of community

A sense of community developed in the group over time. A completer commented that the group understood the difficulty of having chronic pain, which brought a sense of camaraderie,

'We were kind of brothers in arms [....], you feel you're not alone, and you feel that there are other people that, you know, that know what you're going through, and know how difficult it is. [....] We just knew that we were all there, for, for the same purpose.' (G65, completer, D1)

One completer described a sense of trust and empathy within the group, that she felt

understood and benefitted from hearing others' experiences,

'There's a lot of trust in the group as well, so that, that was, a little, a sort of little base [....], if somebody had had a good week, or had a good experience, then you all felt, you know it's a sort of shared happiness, or shared enthusiasm [....]. It was quite open, you really felt you could express yourself, and, and people understood [....]. I found it really, really useful, not just from, you know, just benefitting from other people's experiences as well.' (G47, completer, D2)

#### Appreciation of life and impact on their spirituality

The quality of being present led, for some, to greater appreciation of their surroundings and to being affected on a spiritual level. Spirituality is defined in this paper as the aspect of humanity that governs the way individuals seek and express meaning and purpose and the way they experience connectedness to the moment, to self, others, nature, and the significant or sacred (Puchalski *et al.*, 2014).

One completer felt that practices such as the raisin exercise (eating a raisin mindfully) made her more aware and appreciative of things, such as being able to smell and to see. She spoke about a time when she didn't really see (due to her mental health) or was too busy to notice the beauty around her,

'Just to appreciate really, really appreciate things, because small, small things, you know, these, the things we did, you know, with the raisin, rolling it on your fingers and then on your, it, little things like that, made, made you just, I don't know, much

more aware, [....] for the first time for months, thinking you know, "I can smell, I can see, I can", so there was this sort of um, feeling of um, just contentment and actually engaging with everything that was happening round about.' (G47, completer, D1)

She described a new sense of wonder and awe, when noticing beauty in nature, that brought her fulfilment on a spiritual level,

'It's made me appreciate the fact that you can have spirituality without being in a, because if you are outside, and it is beautiful, and the loch and the hills and birds singing, and things that you hadn't noticed, you know, little things you're seeing, um, yeah, there is a sense of wonder, and awe, and yeah, spirituality. But it's happened out there, it's not, it's not really linked, I wouldn't say to you know, an organised religion [....], it's probably filled that sort of need to have um, something spiritual, something greater.' (G47, completer, D1)

#### 6. Discussion

#### 6.1. Summary of main findings

Participant experiences fell under two categories: factors influencing experience and effects (Figure 2). Factors influencing experience included expectations of achieving pain control, resulting in some participants discontinuing the programme if not met. Those who continued to practice mindfulness beyond the first few weeks and began to incorporate mindfulness into their lives, developed an understanding of how mindfulness relates to pain. They experienced a process of change (see Figure 2 'Effects of the programme'), that involved learning to 'listen to the body', gaining a sense of community, learning to accept their pain, and to approach their lives with more self-care, awareness, appreciation and empowerment. The study supports findings from other studies on the process of change, but makes the novel contribution that understanding the relationship between mindfulness and pain may be a necessary precursor to the process of change. The study also identified particular vulnerabilities of the population, enabling future interventions to be tailored to their needs (Crane et al., 2017). Although findings from completers and non-completers were

analysed separately revealing some differences (see Table 1), experiences often overlapped and some non-completers continued to practice at home, reporting ongoing benefit.

#### 6.2. Comparison with the existing literature

The findings from this study on the effect of mindfulness on pain symptoms are in keeping with recent systematic reviews that found only small and often clinically unimportant improvements (Anheyer *et al.*, 2017; Bawa *et al.*, 2015; Hilton *et al.*, 2017). Although a few participants in our study reported improvements in pain intensity, which they related to being less tense and learning more effective ways to manage their pain, the predominant experience was a process of change (mostly experienced by programme completers, see Table 1) including pain acceptance and empowerment rather than pain reduction. The programme impacted positively on mental health, difficult emotions and other outcomes such as appreciation of life, also in keeping with systematic review findings on depression symptoms (Ball *et al.*, 2017; Hilton *et al.*, 2017). This reflects the aims of non-pharmacological approaches to pain (Turk and Gatchel, 2018).

Some participants had been disbelieved for being in pain during their life, a theme described in previous studies (Mathias, Parry-Jones and Huws, 2014). Having this particular vulnerability led to memories of these experiences being triggered by the programme. Similarly, sense of exclusion due to disability was another vulnerability: disability limited participation leading to a sense of exclusion and discomfort, reminding some participants of this happening earlier in their life. The discomfort from these experiences made dropout more likely (see Table 1: non-completers).

Participants described emotions such as anger and frustration due to their pain condition, which are of particular relevance due to the relationship between emotion and physical pain. Some theories suggest emotional distress as a modulating factor amplifying the severity of pain, as well as the physiological arousal and increased muscle tension associated with anger resulting in increased pain (Gatchel *et al.*, 2007).

The process of change experienced through taking part in the programme, including learning to listen to the body, acceptance, a sense of community or group solidarity, and moving towards greater self-agency or empowerment in managing their condition, has been described in other studies (Long *et al.*, 2016; O'Dowd and Griffith, 2020; Petersen and la Cour, 2016; Ruskin *et al.*, 2017). It may be that the process of change is the way that mindfulness facilitates transition to living with long-term illness, including chronic pain (Long *et al.*, 2016).

The expectation of gaining pain control through the programme and disappointment when this was not achieved, described by completers and non-completers, has also been described previously (Mathias, Parry-Jones and Huws, 2014; Moore and Martin, 2015). Around week four of the programme, an understanding of how mindfulness relates to pain began to develop, mostly among completers, in contrast to the lack of connection with the programme described exclusively by non-completers (see Table 1). The idea that it takes time and practice, to understand that the programme is about changing one's response to experience and to incorporate mindfulness into one's approach to life, has been described in the literature (Ruskin *et al.*, 2017; Schuman-Olivier *et al.*, 2020). This new understanding and incorporation of mindfulness seemed to enable the process of change to occur among completers of our programme, suggesting an emerging model.

Participants in the current study described increased self-awareness through the programme, which was challenging as it required being honest with oneself but rewarding, as it led for some to a sense of self-acceptance also described in the literature (Long *et al.*,

2016). Another study reported a similar phenomenon, with greater awareness of pain eventually leading to acceptance of pain (Luiggi-Hernandez *et al.*, 2018). In contrast to other psychological approaches such as Cognitive Behavioural Therapy (CBT), this challenge may be unique to mindfulness, which involves bringing attention and awareness to uncomfortable experiences rather than employing a strategy to relieve the discomfort (Kabat-Zinn, 2005). This may, in some situations, be overwhelming (Sagula and Rice, 2004).

The impact of the programme on appreciation of life and spirituality may be relevant to the experience of pain described as having a spiritual component, with pain being affected by a search for meaning and purpose (Mehta and Chan, 2008). In the ways described above, mindfulness may enable a holistic approach, addressing emotional and spiritual components of pain, complementary to physical treatments.

#### 6.3. Strengths and limitations

The in-depth nature of the IPA interviewing resulted in data rich with meaning and reflexivity (Willig, 2008), enabling participants' experiences and particular vulnerabilities to be understood. Independent validation of the coding framework identified few areas needing discussion before reaching a consensus.

Limitations included having a self-selected sample (5% of those eligible participated), whose 'vulnerabilities' and life themes may not wholly represent the population with chronic pain, although may be reflective of those who choose to take part in mindfulness programmes. Furthermore, qualitative methods are not intended to be generalisable.

The non-completer experience was diverse, with some dropping out after the first or second week of the programme and not continuing any practices, while some not attending for practical reasons but continuing practices at home. Although these were labelled as noncompleters, they did actually continue practicing. Mindfulness learned through MBSR programmes is intended as a lifelong practice, rather than one that is discontinued after eight weeks, so it may be that measuring session attendance is less representative than measuring continued practice at long term follow-up (Carmody and Baer, 2008).

Researcher knowledge of participant completer status during coding and theming may have influenced the interpretation of findings by seeking systematic differences between the groups. Although using IPA for larger samples favours identification of themes common to a group of people (Smith, Larkin and Flowers, 2009), it may have been more robust to analyse the transcripts blind, with completer status revealed prior to data reporting.

Additionally, only one transcript was double-coded due to resource limitations. Although iterative reviewing of themes generated was conducted by the experienced IPA researcher and the final framework of themes agreed by consensus, double-coding of more transcripts independently prior to discussion would have potentially generated further insights (O'Connor and Joffe, 2020).

The main researcher (initials) being a mindfulness practitioner may have introduced unknown biases in the interpretation of findings. As part of the IPA process, she engaged in 'bracketing' (Denzin, 2001) of preconceptions through recording reflective notes prior to, during and after undertaking interviews. However, complete separation of one's own experience from the interpretation of another person's may not be possible.

The study was conducted in 2013 to 2014, and since then, mindfulness has become a well-established approach to wellbeing in both clinical and non-clinical contexts. If the study was repeated at the present time, attitudes and preconceptions of people entering the programme might be different from our participants due to being familiar with the concept of

mindfulness. This could improve uptake and reduce early drop-out. Additionally, mindfulness practice resources are now easily accessible via online apps and websites, facilitating greater variety of support for home practice. There has also been a general move toward adopting non-pharmacological approaches for the management of chronic primary pain due to lack of evidence of benefit and potential dependency and/or harms from common pharmacological approaches (recent draft guidance by the UK National Institute for Health and Care Excellence (NICE, 2020)). Despite these changes, understanding how mindfulness may benefit people with chronic pain is still under-researched, and this study is a valuable addition to the literature. Further research into mindfulness-based approaches for chronic pain has been recently recommended (NICE, 2020).

#### 6.4. Implications for future research and practice

The process of change identified may be understood through the lens of an established theory such as self-determination theory (Deci and Ryan, 2000). It could be hypothesised that mindfulness acts as a catalyst for the process of change (moving along a trajectory towards integration and acceptance of illness) through increasing the sense of autonomy (being in control and empowerment), relatedness (sense of community) and sense of competence (through relating differently to thoughts, as well as validation by other group members) (Schuman-Olivier *et al.*, 2020). In other words, the factors identified within the process of change appear to be adaptive mechanisms through which a participant transitions to integrating and living with their pain condition. Those who do not realise autonomy, relatedness and competence from the programme would not develop the motivation to practice mindfulness, and would be more likely to drop out of the programme. Therefore, optimising these factors may improve motivation to engage with the programme. The contribution of these and other factors could be explored in future studies.

Additionally, given the aims of non-pharmacological approaches to chronic pain to promote self-management, adaptation and coping, it is recommended that future trials measure more relevant outcomes. These could include validated measures such as the Pain Resilience Scale (PRS) (Ankawi *et al.*, 2017) and Chronic Pain Acceptance scale (CPAQ) (McCracken, Vowles and Eccleston, 2004).

#### 7. Conclusion

Participants reported a variety of experiences of the programme. Expectations of pain control led to some participants dropping out. Those who remained and incorporated mindfulness into their lives gained an understanding of how mindfulness relates to pain and went through a process of change involving acceptance, awareness, appreciation and sense of community which may have supported them in living with their pain condition. This contributes to our understanding of how mindfulness could benefit people with chronic pain.

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### Greyscale figures for printed version (if printed in black and white)

Fig. 1. Flow chart of recruitment, retention and data collection



Fig. 2. Participant experiences of the mindfulness programme