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# **A pluralistic approach to medically unexplained symptoms**

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Portfolio submitted in fulfilment of the  
Professional Doctorate in Counselling Psychology (DPsych)

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## List of abbreviations

|               |                                                               |
|---------------|---------------------------------------------------------------|
| ME/CFS        | Myalgic Encephalomyelitis/Chronic Fatigue Syndrome            |
| MBIs          | Mindfulness-Based Interventions                               |
| WHO           | World Health Organisation                                     |
| MEA           | The ME Association                                            |
| NICE          | National Institute for Health and Clinical Excellence         |
| MBSR          | Mindfulness-Based Stress Reduction                            |
| MBCT          | Mindfulness-Based Cognitive Therapy                           |
| ACT           | Acceptance and Commitment Therapy                             |
| CFT           | Compassion-Focussed Therapy                                   |
| DBT           | Dialectical Behaviour Therapy                                 |
| IBS           | Irritable Bowel Syndrome                                      |
| BPM           | Buddhist Psychological Model                                  |
| S-ART         | Self-Awareness, Self-Regulation, and Self-Transcendence Model |
| EES           | The Enactive Experiential Self                                |
| EPS           | The Experiential Phenomenological Self                        |
| NS            | The Evaluative Narrative Self                                 |
| BPS           | The British Psychological Society                             |
| IPA           | Interpretative Phenomenological Analysis                      |
| RAIN Practice | Recognise, Allow, Investigate, Non-Identify Practice          |
| UKCP          | United Kingdom Council for Psychotherapy                      |

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Mum and dad, there are no words, thank you, thank you, a thousand times.

And finally, Charlie, you are loved and missed.

## Preface

“It’s not just science, there’s a bit of an art to it”

- Caroline: Research Participant

This doctoral portfolio takes a pluralistic approach to medically unexplained symptoms. Pluralism is the idea that there is no one overarching ‘truth’ but a variety of ‘truths’, each with the potential to be as important as another. It is a philosophy frequently adopted by the counselling psychology profession and there appears a functional component to how counselling psychologists utilise it, using the flexibility it affords to choose what they believe to be the best model and the best in-situ interventions for the client in-front of them. In this portfolio I illustrate the pluralistic ethos in vivo, applying this philosophical stance to counselling psychology work both in research and in the therapy room. Medically unexplained symptoms, the other facet linking the three pieces contained within this portfolio, are considered via the field of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and in a gentleman living with Parkinson’s disease. Each piece was completed during training at City University London and is hoped to evidence the skills I have learnt during the course.

The first section presents an original piece of research which asked “How are mindfulness-based interventions experienced by people with ME/CFS”. The epistemology and methodology used within the research were chosen consistent with counselling psychologists’ use of pluralism, being selected based upon what I believed best-placed to achieve my intentions for the study. My hopes for the research went beyond the level of the research question to the wider social context, aims not only being centred on what I hoped to find out but on what I wanted the research to communicate about me as a person and a practitioner. It felt important that this study, which would come to represent a communication to the world about

who I am, embodied my personal beliefs and who I strive to be as a counselling psychologist. With this in mind, the epistemological stance of a critical realist was adopted and the methodology Interpretative Phenomenological Analysis utilised. The subject matter, ME/CFS, is one close to my heart and one in which I believe it is important to pay homage to qualitative methodology. In my opinion, the qualitative approach affords us a vessel through which we can communicate our willingness to listen to and engage with the voices of people with ME/CFS. As hoped, the result of the study is a nuanced and detailed account of the phenomenon from which many practical implications for future practice and research emerged.

The publishable piece presented in the second section was again chosen in accordance with counselling psychologists' pluralistic stance. The article is entitled "I was quite a cynic initially": People with ME/CFS' struggles with doubts and understanding in mindfulness-based interventions', and illustrates one of the four themes highlighted in the main research. A number of pieces could have been written and this one was chosen with functionality in mind, being believed particularly pertinent to client outcome and to espouse practical steps which can be taken to improve intervention. This focus was thought appropriate for the journal 'Mindfulness' which states its aims as advancing "research, clinical practice, and theory on mindfulness" (see Appendix A for a shortened version of the journal's submission requirements). Writing-up for a journal requires a different style and, to some extent, different content to writing-up for a thesis. Counselling psychologists' flexibility is therefore displayed here in my adaptation to the academic style – using third person narrative and focussing less on the methodology in favour of the findings. The lens on medically unexplained symptoms remains the same – the exploration of ME/CFS.

The third and final section of this portfolio looks at medically unexplained symptoms through a different lens. Rather than participants living with ME/CFS we meet Ray, a gentleman diagnosed with Parkinson's disease yet whose difficulties with walking were thought heavily influenced by psychological factors. Ray appeared to espouse experiences similar to those described by my research participants and/or considered frequently in the ME/CFS literature. Interactions with medical professionals, anxiety around illness, and striving above all to get better seemed pertinent to Ray also. Again, similar to my research participants and literature concerning ME/CFS, the question of 'to what extent do symptoms have a biological aetiology' seemed important to Ray and I. Ray's account gives a different perspective to these themes, and the reader is afforded insight into what they meant to us both in the context of psychological therapy.

Through this account of Ray and my time together, I also illustrate how counselling psychologists' pluralistic ethos can be navigated and upheld in the therapeutic setting. Readers can see how pluralism shaped the therapeutic work from formulation, to in-situ intervention, to supervision. The steps taken to develop an individualised therapeutic model are described and how this is used to understand Ray's difficulties espoused. The in-situ use of this model and the therapeutic 'techniques' included within it are explored, and different facets of supervision considered. Throughout the narrative, a story of how I battled against the medical model of therapy, the 'therapy as a pill' conceptualisation, is told.

Rather than a 'pill', counselling psychologists understand therapy as a dialogue, a dynamic interaction between the therapist and client. The same understanding is applied to research as findings are conceptualised to be a product of both the participant and the researcher. In these situations our self becomes a tool, and to utilise this to best effect we need to know ourselves to a certain depth of understanding. In knowing ourselves we can learn about the other. As is typical for

the counselling psychologist therefore, each piece in this portfolio contains some element of reflection. As a result, the portfolio not only illustrates what I have learned about the areas it considers, but explores the knowledge I gained about myself through the process.

Interestingly, I found it was not just the 'doing' (i.e. the analysing, the therapeutic work) which was a learning process but the writing up, the pulling together of the experience, that taught me much about myself. As each piece was brought together I viewed my experience through a new lens, a different viewpoint one stage removed from the doing of the process. It is my intention that engaging with this portfolio will afford the reader a new perspective also. Hopefully in their consideration of my work, they will gain new insights into pluralism and medically unexplained symptoms. Further, I wish the portfolio to spark the reader's own reflection, and through this for useful implications for the reader's own life and work to emerge.

## **Declaration**

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## **Part One – Doctoral research**

### ***Experiencing mindfulness-based interventions whilst living with ME/CFS: An Interpretative Phenomenological Analysis***

#### **Abstract**

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is associated with physical, cognitive and emotional challenges, and much research suggests that mindfulness-based interventions (MBIs) can be helpful for these difficulties. It is reasonable to assume that living with ME/CFS influences how people experience MBIs. However, existing literature provides little insight into what it is like to attend an MBI if experiencing ME/CFS and thus there is a paucity of information to guide intervention. The current research aimed to elucidate this experience by applying Interpretative Phenomenological Analysis to eight interview transcripts. Four master themes - 'The gift of mindfulness', 'Struggling with doubts and understanding', 'The vulnerable self', and 'Healing relationships' - emerged. Individuals gave complex reports of MBIs which encompassed both positive and negative accounts. Throughout these accounts, ME/CFS appeared at the forefront of individuals' perceptions as if it were a lens they viewed their experiences through. For some, mindfulness gifted acceptance, ways of self-soothing and methods of regaining control. Many participants struggled with mindfulness however, fighting with their own internal barriers and finding the guidance they were given confusing. Being at the MBIs seemed to automatically place individuals in a vulnerable position. Participants reported that it was essential for them to 'be on guard', to monitor their activity and environment in regards to illness exacerbation. Indeed, many individuals seemed to expect the worst from the MBIs, particularly from the attitudes of their course peers and facilitators. In contrast to participants' expectations, individuals commonly reported that their facilitators and peers understood their

conditions and experiences. This sense of being validated and of belonging was reported to be therapeutic. Moreover, relationships with others on the course were found to elicit a sense of hope and helped individuals engage with the mindfulness material. Best practice recommendations include reducing participants' anxieties and managing expectations around MBIs as well as harnessing the power of the group. Future research might further explore discourses around MBIs, the group dynamics involved, hope, demographic differences, and the potential utility of Acceptance and Commitment Therapy for ME/CFS.

## **1. Introduction**

The current research project explores how mindfulness-based interventions (MBIs) are experienced by people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). It aims to address the current gap in the literature and the lack of knowledge about the nuances of this phenomenon – what it is like, what people, environments or events are salient and why they might be so. The following section provides an overview of ME/CFS, its symptoms and its impact upon life and self-identity as well as an overview of MBIs, which ones are currently available and how they are thought to elicit change. I describe what I believe is not known by current research and explain how the present study addresses this deficit.

### ***1.1 Myalgic encephalomyelitis/chronic fatigue syndrome***

Approximately 150,000 to 250,000 people in the UK are thought to be living with ME/CFS, which appears to onset mostly between the ages of 10 to 60 (Shepherd & Chaudhuri, 2011; Dowsett et al., as cited in Shepherd, 1998). It is believed that about 75% develop the condition between their late teens and early forties (Shepherd, 1998). According to Nacul et al. (2011), ME/CFS is more common in women. The likelihood of a full recovery is estimated as low. When reviewing 28 studies, Cairns and Hotopf (2005) found a median full recovery rate of seven percent. Just under 40% of participants appeared to experience improvements rather than full recovery (Cairns and Hotopf, 2005).

ME/CFS is known to be connected with low mood and positively correlated with higher scores on depression measures (Eglinton & Chung, 2011; Shepherd & Chaudhuri, 2009; Komaroff et al., 1996). A plethora of research reports individuals experiencing emotional distress as a result of living with the condition (e.g. Eglinton & Chung, 2011; Anderson, Jason, Hlavaty, Porter & Cudia, 2011; Arroll & Senior,

2008; Dickson, Knussen & Flowers, 2008; Ward, Hogan, Stuart & Singleton, 2008; Whitehead, 2006; Lombaard & Mouton, 2005).

No single cause for ME/CFS has been found and, as stated by Poppe, Petrovic, Vogelaers and Crombez (2013) and Eglinton and Chung (2011), many researchers adopt a bio-psycho-social attitude to its development and maintenance. Biologically, research indicates a likely neurological aetiology (disorder in the nervous system) (Morris & Maes, 2013; World Health Organisation [WHO], 2007). It is currently thought that factors such as genetic vulnerability, viral illnesses (such as the common cold), toxic poisoning and stress precipitate onset (Perry & Santhouse, 2012; Shepherd, 1998). Anecdotal evidence suggests that some vaccinations can trigger onset also (Shepherd, 1998). Regarding psychological and social contributors, research indicates a number of factors including 'maladaptive' schemas or cognitions and aversive life events. For example, one study found 47.5% of participants diagnosed with ME/CFS endorsed the schema 'unrelenting standards' to a significant level compared with 25% of controls (Stalmeisters & Brannigan, 2011). Wearden and Emsley (2013) found reductions in fear avoidance and embarrassment avoidance to mediate improvements in fatigue. In a similar vein, Valero, Saez-Francas, Calvo, Alegre and Casas (2013) found depression severity to mediate effects that neuroticism had upon fatigue severity in 229 individuals diagnosed with ME/CFS. Again, Eglinton and Chung (2011) found over a third of their sample of individuals with ME/CFS met the criteria for full post-traumatic stress disorder (PTSD) and an additional one-fifth met the criteria for partial PTSD.

People with ME/CFS appear to experience a range of symptoms, the most common of which seems to be severe and disabling fatigue, a symptom that Fukuda et al. (1994) argue diagnosis cannot be made without. One participant in Arroll and Senior's study (2008, p. 448) described fatigue as a "lack of stamina" rather than a

tiredness, characterised by tiring quickly rather than being tired all the time. Individuals report that fatigue also manifests physically in their muscles, as well as in 'cognitive dysfunction' characterised by poor concentration, impaired problem-solving skills, word-finding difficulties, dizziness and loss of memory (Morris & Maes, 2013; the ME Association [MEA], 2010; Arroll & Senior, 2008; Lovell, 1999). Other commonly reported symptoms include a sore throat, swollen glands, digestive problems, pain, headaches and poor or dysregulated sleep (Morris & Maes, 2013; Shepherd, 1998). Many report sensitivities to medication (Shepherd, 1998).

Symptoms appear to vary in everyday life and over longer periods of time, sometimes for no apparent reason and other times as a result of activity (Arroll & Senior, 2008). As outlined in Morris and Maes (2013), even trivial increases in physical or mental activity above a level of tolerance can result in symptom exacerbation. It seems the line between what can and cannot be tolerated is subjective and often mysterious (Arroll & Senior, 2008) thus exacerbation is not always predictable or controllable. One common experience appears to be engagement in 'boom and bust' behaviour, whereby individuals follow a pattern of pushing themselves over their limit, often when feeling better, which leads to exacerbated symptoms and a subsequent convalescent period at a lower level of functioning (Edwards, Thompson & Blair, 2007; National Institute for Health and Clinical Excellence [NICE], 2007).

As mentioned above, developing and living with ME/CFS can significantly impact an individual's mood. Other research sheds further light on this, suggesting that individuals' identities and self-relationships are particularly impacted by the condition. Studies by Brooks, King and Wearden (2014), Dickson et al. (2008) and Asbring (2001) report participants describing a discrepancy between the individuals they perceived themselves to be before and after onset. Individuals with ME/CFS have described themselves as not their 'true' selves or as embodying their real

identities (Brooks et al., 2014) Similarly, people have talked about experiencing an absence of identity - being unsure of who or what they were when the experience and presence of ME/CFS is put aside (Dickson et al., 2008). ME/CFS is often referred to as something outside one's identity. Dickson et al. (2008) report participants describing themselves as witnesses or hosts to their condition, one woman personified her ME/CFS as a "dictator" (p. 463). Many expressed not wanting to be the people they were (with ME/CFS). Instead they desired their former pre-onset selves or the selves they once expected to be (Dickson et al., 2008; Asbring, 2001). Individuals have reported a sense of alienation within themselves. For example, participants in Dickson et al. (2008) expressed an inability to access their own minds and bodies and one individual in Arroll and Senior (2008) described feeling unsafe within her body and unsure how to return to a secure place. Individuals have described that their body has become a stranger and that they feel it has been failing them (Lombaard & Mouton, 2005).

### ***1.2 Mindfulness-based interventions***

To outline the MBIs utilised in psychology at present, it first seems appropriate to explain what the field means by 'mindfulness'. There appears to be consensus that definitions vary (e.g. Vago & Silbersweig, 2012; Coffey, Hartman & Fredrickson, 2010) and many authors use a quote by Jon Kabat-Zinn, the founder of the mindfulness-based stress reduction (MBSR) programme, to introduce and explain the concept. Kabat-Zinn describes mindfulness as "paying attention in a particular way: on purpose, in the present moment, and non-judgementally" (Kabat-Zinn, 1994, p. 4). Through systematic analysis researchers have sought to create a comprehensive definition to be used across studies. Findings from one such study, a factor analysis conducted by Coffey et al. (2010), indicate that mindfulness can be understood to consist of two elements – "attention to present experience" and "acceptance of internal experience".

In practice, mindfulness involves guiding one's focus to the five senses or to cognitions - the thoughts, memories and images present within the mind (Harris, 2009). One explores the focus of their attention "like a curious scientist" who has never encountered it before (Harris, 2009, p. 114). The aim is to consider one's experience compassionately, noticing judgements yet attempting to let these go without attachment, as one would watch cars passing by outside their house (Harris, 2009). Mindfulness aims not to change an experience but to accept it as it is in the moment. This may seem counterintuitive considering mindfulness is frequently used in interventions; actions designed to reduce distress. Ironically, however, research often finds that distress lessens when individuals work to accept experience as it is (Harris, 2006).

Mindfulness is commonly engaged with in 'formal' practice, frequently referred to as 'meditation' or 'mindfulness meditation'. Here individuals spend time sitting/lying down and focussing their attention on present-moment experiences as described above. Mindfulness can be formally practiced with or without assistance, e.g. an audio-recorded guide. Mindfulness is also frequently engaged with in 'informal' practice. Here individuals focus their attention 'mindfully' on activities in daily life. An example might be brushing one's teeth – attending to what the toothpaste tastes like and bristles feel like. Additionally, mindfulness is commonly understood as a philosophy. Here the attitude of noticing, treating with compassion and accepting is used as a baseline from which to engage with the world.

There are many other understandings of mindfulness presented within the literature, some of which are reviewed here. One is mindfulness as a religious practice. For example, authors such as Hollis-Walker and Colosimo (2011), Koole, Govorun, Cheng and Galluci (2009), Khong (2009), Tophoff (2006) and Andersen (2005) imply that mindfulness originated from Buddhism or describe mindfulness from a Buddhist perspective. Similarly, Friedman (2010) argues mindfulness is present

within Jewish Kabbalistic, Chinese Daoist and Hindu yogic traditions. Another understanding is mindfulness as an innate ability (e.g. Vago & Silbersweig, 2012; Coffey et al., 2010; Williams, 2010). A final perception, as mentioned above, is a stand-alone technique or intervention, a conceptualisation prominent in many modern psychological approaches (Khong, 2009).

It seems that mindfulness gained prominence in Psychology during the birth of 'third wave' cognitive-behavioural therapy (CBT) in the late 1970s. Third wave CBT is so called because the models understood to comprise the approach encapsulate a third paradigm of thinking in the CBT School. The first 'wave' of CBT began in the 1940s, behavioural therapy underpinned by Skinner and his work on stimulus-response reactions (Suffolk Cognitive Behavioural, 2006). The second 'wave' arose in the late 1960s, and is understood to encapsulate modern CBT as it is traditionally used today, the behavioural basis of Skinner entwined with the cognitive theories of Aaron Beck and Albert Ellis (Suffolk Cognitive Behavioural, 2006). The third 'wave' is characterised by the movement of mindfulness into the field and the development of new intervention models integrating mindfulness and traditional CBT (Guarna, 2006).

Numerous MBIs exist, arguably the most common being MBSR, mindfulness-based cognitive therapy (MBCT), acceptance and commitment therapy (ACT), compassion-focussed therapy (CFT) and dialectical behaviour therapy (DBT). Jon Kabat-Zinn developed MBSR in 1979 (Cullen, 2011). It is a treatment protocol delivered in a group format over eight weeks and was designed for individuals with a variety of difficulties including chronic pain, hypertension, heart disease, cancer, gastrointestinal disorders, anxiety and panic (Prince of Wales International Centre, n.d). Cullen (2011) states that MBSR uses three formal meditations, (mindful movement, body scan and sitting meditation), and promotes regular practice and the application of teaching in daily life.

MBCT is also a treatment protocol delivered in a group format over eight weeks. It is based on Kabat-Zinn's MBSR programme and was developed by Zindel Segal, Mark Williams and John Teasdale early this century (Segal, Williams & Teasdale, 2002). MBCT was specifically designed to help individuals experiencing repeated periods of low mood to learn relapse prevention skills (Prince of Wales International Centre, n.d; Malpass et al., 2011). According to Grabovac, Lau and Willett (2011) MBCT focuses on decreasing rumination by developing awareness of cognitions/sensations and our thoughts about these. Clients are encouraged to consciously respond to cognitions/sensations with self-care. This could mean purposely switching attention to a neutral focus or deliberately engaging in activities which provide pleasure or a sense of efficacy (Grabovac et al., 2011).

ACT was developed by Steven Hayes in 1986 (Harris, 2006). It is a model of therapy applicable to couples, individuals and groups, in brief or long-term contexts, and to a wide range of presentations. The model affords the therapist flexibility, allowing them to design their own interventions and mindfulness techniques. According to Grabovac et al. (2011) ACT understands mindfulness as four interrelated processes. First is acceptance, allowing internal events to be as they are without seeking to modify them. Second is defusion, the act of understanding one's inner experiences as temporary mental events rather than accurate and true reflections of the world. Third is contact with the present moment, a conscious awareness of present stimuli moment to moment. Fourth is the observing self, the 'you' continuously present and from whose perspective one can observe their inner experiences (Grabovac et al., 2011; Harris, 2009).

According to Gilbert (2009), compassion and its potential for healing have been written about for centuries and began to be considered by Western Psychology early this century. Similar to ACT, CFT is a model of therapy with wide application. Again, the therapist works flexibly. Their role is to provide a space where the client

can feel safe with the therapist, to help clients tolerate and feel safe with the information discussed in therapy, and to utilise kindness rather than self-criticism (Gilbert, 2007). Central to CFT is compassionate mind training whereby the therapist and client engage in activities designed to develop compassionate attributes and skills (Gilbert, 2009). Mindfulness is central to many of these activities (Gilbert, 2010).

DBT was developed in the late 80s by Marsha Linehan (Psych Central, 2007). Originally designed for the chronically suicidal, DBT is now mostly used with individuals diagnosed with borderline personality disorder who experience a range of difficulties including emotional dysregulation, substance dependence and binge eating (Dimeff & Linehan, 2001). In DBT, mindfulness is used to encourage acceptance, pay attention to the present moment, assume a non-judgemental stance and consider the interpersonal effectiveness of behaviour (Dimeff & Linehan, 2001). DBT typically includes a combination of group skills training and individual therapy. Here again the therapist works flexibly rather than to a protocol (Harris, 2006).

Many other MBIs have developed since the beginning of the third wave. Cullen (2011) lists 13 established protocols including mindfulness-based EAT (Kristeller & Hallett, 1999), mindfulness-based elder care (McBee, 2008) and mindfulness-based relapse prevention (Bowen, Chawla & Marlatt, 2011). It seems practitioners have also developed personal protocols based on the approaches and literature detailed above. For example, participants in Stelter (2009) were recruited from “mindfulness meditation training courses” designed by course facilitators around the work of Kabat-Zinn, Ferris, Urbanowski, Williams, Teasdale and Segal. Similarly, Felton, Coates and Chambers-Christopher (2013) survey a course entitled “Mind-Body Medicine and the Art of Self-Care”, which appears to have been developed by a faculty member and based loosely on MBSR.

### **1.3 Benefits of MBI**

A plethora of research exists which investigates the effects of mindfulness and MBIs in a wide variety of samples and presentations. This depicts promising results. Below literature detailing eight areas is reviewed. These areas are pain, fatigue, cognitive functioning, digestive problems, headaches/migraines, sleep, mood and stress. As described earlier, these are known to be pertinent to the experience of ME/CFS. An overview of research which has specifically considered MBIs and ME/CFS together is then presented.

ACT has been found to reduce pain-related anxiety and disability, the number of medical visits and painkillers prescribed in individuals experiencing chronic pain (Vowles, Witkiewitz, Sowden & Ashworth, 2014; McCracken, Sato & Taylor, 2013). Lauche, Cramer, Dobos, Langhorst and Schmidt (2013) suggest MBSR might be a helpful approach for individuals diagnosed with fibromyalgia and Rosenzweig et al. (2010) found improvements in pain intensity and functional limitations due to pain in individuals with back/neck pain after MBSR. Similarly, Bedard et al. (2012) found reduced pain intensity scores in individuals with traumatic brain injuries after MBCT. Gardner-Nix, Barbati, Grummitt, Pukal and Newton (2012) found a mindfulness-based pain management course to reduce levels of suffering due to chronic pain.

Bohlmeijer, Fledderus, Rokx and Pieters (2011) found a reduction in fatigue scores for individuals with depressive symptomatology after ACT intervention. Carlson and Garland (2005) also report fatigue reduction in individuals with cancer after MBSR. Similarly, van der Lee and Garssen (2012) found reductions in fatigue after MBCT for cancer survivors. Moreover, Zeidan, Johnson, Diamond, David and Goolkasian (2010) report that brief mindfulness training reduced fatigue in university students with no prior mindfulness experience.

Regarding cognitive functioning, Johansson, Bjuhr and Ronnback (2012) found improvements in mental fatigue after MBSR in individuals with traumatic brain injuries. Ives-Deliperi, Howells, Stein, Meintjes and Horn (2013) found improvements in both working and spatial memory and verbal fluency after MBCT in individuals diagnosed with bi-polar disorder. Similarly, Zeidan et al. (2010) found brief mindfulness meditation to improve visuo-spatial programming, working memory and executive functioning in university students.

Findings from Kearney, McDermott, Martinez and Simpson (2011) suggest MBSR is associated with better irritable bowel syndrome (IBS)-related quality of life. Similarly, Garland et al. (2012) found decreased symptom severity and improved IBS quality of life after MBSR tailored specifically to IBS. Ljotsson et al. (2010a) found improvements in bloating, pain and diarrhoea in 50% of individuals with IBS after a 10-week exposure and mindfulness intervention. In a similar vein, Ljotsson et al. (2010b) found internet-delivered CBT based on exposure and mindfulness exercises to yield a 42% decrease in IBS symptoms. A meta-analysis by Lakhan and Schofield (2013) found mindfulness-based therapy particularly beneficial for pain and symptom severity in individuals with IBS.

Dindo, Recober, Marchman, Turvey and O'Hara (2012) reported that ACT training plus migraine education elicited improvements in migraine-related disabilities. Schmidt, Simshäuser, Aickin, Luking and Schultz (2010) found reductions in impairment due to migraine and medication use after MBSR. Similarly, studies conducted by Day and colleagues (Day, Thorn & Rubin, 2014; Day et al., 2014) report MBCT adapted for use in migraine can improve scores in pain interference, self-efficacy and pain acceptance and catastrophizing. Moreover, Cathcart, Galatis, Immink, Proeve & Petkov (2014) found decreases in headache frequency after brief mindfulness-based therapy in individuals experiencing chronic tension-type headaches.

A case study by Dalrymple, Fiorentino, Politi and Posner (2010) reported that an integration of ACT and CBT for Insomnia yielded successful treatment results. Carlson and Garland (2005) also found improvements in self-reported sleep scores for individuals with cancer after MBSR. Similarly, Gross et al. (2011) found improvements in time to sleep onset, insomnia severity, sleep quality and sleep efficiency post MBSR in individuals experiencing chronic insomnia. Again, Frank, Reibel, Broderick, Cantrell and Metz (2013) found improvements in sleep duration and disturbance, time until sleep onset and perceived sleep quality in teachers after MBSR. Similarly, Yook et al. (2008) found MBCT to improve the quality of sleep in individuals diagnosed with anxiety disorders.

Regarding mood, ACT has been found to reduce anxiety, depression and stress scores and increase quality of life scores (McCracken et al., 2013; Swain, Hancock, Hainsworth & Bowman, 2013; Folke, Parling & Melin, 2012; Yadavaia & Hayes, 2012). Participants in these studies experienced anxiety disorders, long-term sick leave, chronic pain and self-stigmatisation due to sexual orientation. MBSR has been found to reduce mood disturbance scores in individuals with cancer (Carlson & Garland, 2005) and improve anxiety and depression scores in primary school teachers (Gold et al., 2010). MBCT has been found to be a partial mediator of improvements in depressive symptoms for individuals with partially remitted depression (Britton, Shahar, Szepsenwol & Jacobs, 2012), to reduce depressive symptoms and relapse in individuals with major depression (Chiesa & Serretti, 2011) and to reduce anxiety symptoms in individuals with bi-polar disorder and some anxiety disorders (McManus, Surawy, Muse, Vazquez-Montes & Williams, 2012; Chiesa & Serretti, 2011). Krieger, Altenstein, Baettig, Doerig and Grosse-Holtforth (2013) found individuals with higher self-compassion less likely to experience depressive symptomatology and a review by Hofmann, Grossman and

Hinton (2011) concluded that loving kindness and compassion meditations were associated with increased 'positive' and decreased 'negative' emotion.

Brinkborg, Michanek, Hesser and Berglund (2011) found lowered levels of stress and burnout in social workers after brief ACT-based stress reduction intervention. Carlson and Garland (2005) found reduced stress scores in individuals with cancer and Gold et al. (2010) reported improvements in the stress levels of primary school teachers after MBSR. Britton et al. (2012) found lower levels of emotional reactivity to stress in individuals with partially remitted depression after MBCT. Finally, Hofmann et al. (2011) concluded that compassion meditation may reduce stress-induced subjective distress.

It appears that little research exists exploring the usefulness of MBIs for individuals with ME/CFS. Three quantitative studies have been conducted and indicate some promising results. The first was by Surawy, Roberts and Silver (2005). They ran three exploratory studies designed to investigate the effects of an eight-week intervention based on MBSR and MBCT. The third of these studies differed from the initial two as new information was presented during the course which related to cognitions and physical activity. This was more typical of the MBCT style. Measures were also re-administered at a three-month follow-up in the third study whereas follow-up measures were not administered in the initial two. In all studies, participants completed measures of anxiety, depression, physical functioning, fatigue and quality of life. Participants' opinions regarding how acceptable they found the course were collated also.

Surawy et al. (2005) stated that the interventions were reported as highly acceptable to participants in each of the three studies. Anxiety scores were found to reduce in each study and to be maintained at a three-month follow-up. Although depression scores did not change in studies one and two they were found to

decrease in study three and maintained this decrease at the follow-up. Similarly, physical functioning scores did not change in studies one and two but did improve in study three and were maintained at the follow-up. Fatigue scores decreased in studies one and two but not to a statistically significant extent. Fatigue scores did significantly decrease in study three and this was maintained at the follow-up. A further measure was administered in studies two and three which assessed the effects of fatigue on quality of life. Analysis revealed the intervention to significantly reduce the impact of fatigue on participants' lives in both these studies. Benefits were again maintained at the follow-up.

Although Surawy et al. (2005) indicated that MBIs may be useful for individuals with ME/CFS, they said little about the content of the MBIs investigated rendering it difficult to consider their research alongside other research or interventions. Also the sample sizes used were small - nine participants completed measures in each study and eight at the follow-up. This suggests that the generalizability of findings is questionable.<sup>1</sup>

The second study, conducted by Sampalli, Berlasso, Fox and Petter (2009) gives more detail about the MBI investigated. The "Body Mind Awareness Program" was based on an MBSR model and ran for 10 weeks. Session eight was reserved as a six-hour silent retreat. Sessions consisted of mindfulness meditations, discussions regarding these and individuals' experiences and psycho-education about stress and emotions. Individuals were expected to commit to formal and informal homework practice and audio-recordings were provided to this end. Participants completed measures of somatisation, obsessive-compulsiveness, interpersonal sensitivity, depression, anxiety, hostility, phobic responses, paranoid responses,

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<sup>1</sup> This evaluation is based on the assumption that generalisability is a valid concept. Although much research assumes that if a sample is big enough findings can be generalised to most (usually 90-95%) individuals outside of the sample, other researchers argue that generalising to individuals outside of a sample is invalid, no matter how many individuals are included in the study.

psychotic responses and the global severity of these variables before, after, and three months post intervention. Analysis revealed improvements in overall severity ratings post-intervention and at the follow-ups. Improvements were observed in somatisation, depression, phobic anxiety and paranoid ideation scores post-intervention. These maintained significance at the follow-ups and scores in obsessive-compulsiveness, interpersonal sensitivity, anxiety and psychotic responses also reached significance at this point.

Although Sampalli et al. (2009) used a larger sample size of 50, this again appears small when looking to generalise findings. Participants were all female and though it seems the majority were diagnosed with ME/CFS or ME/CFS and fibromyalgia or multi-chemical sensitivity, exactly how many in each category remains unclear. Generalisability is also therefore questionable in this study.

Perhaps with the exception of somatisation, Sampalli et al. (2009) appear to focus on the psychological impacts of intervention. Similar to Surawy et al. (2005), the third study to consider MBIs and ME/CFS together focussed on physical variables as well as psychological. Rimes and Wingrove (2011) included measures of fatigue, general impairment and physical functioning in their research. Arguably more so than Surawy et al. (2005) and Sampalli et al. (2009), Rimes and Wingrove (2011) chose measures tailored to the experiences of ME/CFS. They measured beliefs about emotions, 'boom and bust' behaviour and catastrophic thinking about fatigue, all found to be pertinent and common phenomena to individuals with ME/CFS (Rimes and Wingrove, 2011). Remaining questionnaires measured self-compassion, mindfulness, anxiety and depression. Rimes and Wingrove (2011) further considered the acceptability of the interventions. They asked participants about how useful the mindfulness course had been for them, monitored attendance and measured their engagement with home practice and the allocated reading.

Rimes and Wingrove (2011) produced perhaps a more comprehensive view of follow-up than Surawy et al. (2005) and Sampalli et al. (2009), re-administering measures at two- and six-months post-intervention. Participants were individuals still experiencing excessive fatigue after up to 12 sessions of individualised CBT. They engaged in an MBCT intervention, which involved an introductory session and eight following weekly sessions. Intervention included mindfulness meditation practices, discussion around practices and individuals' experiences and expected home practice with the use of CDs. Intervention was adapted so psycho-educative and cognitive components were consistent with a CBT model of ME/CFS, rather than MBCT's traditional focus on depression. Again, a small sample size was used (16 in treatment group).

Analysis revealed that all participants rated the intervention as "useful" or "very useful". Scores on fatigue, catastrophic thinking, 'boom and bust' behaviour, self-compassion, impairment and mindfulness improved post-intervention and were maintained at a six-month follow-up. Beliefs about emotions were found to change too. Particularly, participants were found to hold fewer beliefs thought to be unhelpful. Depression scores improved post-treatment but were not maintained at the two-month follow-up. Although depression scores were notably better at the six-month follow-up than pre-treatment they were not significant at this point either. Physical functioning and anxiety scores were not significantly different from before to after treatment or at either follow-up although a non-significant improvement was notable in physical functioning from pre-treatment to six-months.

These studies can be further critiqued on two accounts. First, although Surawy et al. (2005) and Rimes and Wingrove (2011) appear to measure "acceptability", the validity of their measures appears questionable. Surawy et al. (2005) used a likert scale which asked participants to rate course components from 0 (not at all useful) to 10 (very useful). As mentioned above, Rimes and Wingrove (2011) appeared to

use class attendance, engagement in home practice and the amount of hand-outs read. They also asked the question “how useful has the mindfulness course been to you” with options of “no use at all”, “quite useful”, “useful”, “moderately useful” and “very useful”. Although Rimes and Wingrove (2011) seemed to collect some qualitative data this appeared to centre specifically on home practice and was not discussed further in their write-up. It could be argued that such measures are unlikely to collect enough information from which to draw accurate conclusions. For example, acceptability might encompass appropriateness to individuals’ religious backgrounds and perceptions of the facilitator’s attitude and teaching style. Acceptability might also consider necessary, and perhaps unwanted, adaptations to incorporate sessions and home practice into life. Maybe individuals forewent other activities to ensure energy levels were not detrimentally reduced by sessions and home practice. Perhaps future studies would benefit from more inclusive measures.

Second, it may be that samples are biased towards those not experiencing severe ME/CFS. The MEA (as cited in Dayes, 2011) highlights that it can be difficult to generate representative samples as severely affected individuals may be unable to engage in the research process. Indeed, it could be that the difficulties that those severely affected might experience in completing MBIs biases results from the aforementioned studies towards less severely affected individuals. For example, although they do not explain why or how many, Surawy et al. (2005) report excluding individuals unable to travel to the group. Similarly, although they do not report why, Rimes and Wingrove (2011) excluded nine people unable to attend regularly. Again, Sampalli et al. (2009) reported that 16% dropped out of their intervention due to work/family commitments and ill health. Further, such drop out/exclusion statistics may also question conclusions about acceptability as responses were gathered only from participants who completed the intervention, not individuals who dropped out or were excluded at outset.

A small body of literature has investigated the role of acceptance in ME/CFS. This is notable as acceptance is understood as a central facet of mindfulness (e.g. Coffey et al., 2010). Both qualitative and quantitative investigations have been conducted. Findings from the quantitative literature, which tends to explore the effects of acceptance variables upon ME/CFS-related factors, appear somewhat mixed. While findings from the qualitative literature, which tends to explore how ME/CFS is experienced, appear more consistent.

In the qualitative literature, studies indicate that acceptance is a positive endeavour. In papers written by Asbring (2001) and Whitehead (2006) individuals appear to describe much distress when feeling non-accepting towards their illness. Conversely, life seems to improve when individuals begin to accept ME/CFS and consequently manage it. Present within both these studies was a sense of gaining from the illness. For some, learning to live with ME/CFS appeared to be the catalyst for positive change. Specifically, participants spoke about becoming stronger, more confident and more assertive (Whitehead, 2006) as well as gaining increased self-respect and personal integrity plus greater understanding of their self and others (Asbring, 2001). Findings from Dickson et al. (2008) reflect the above. The researchers reported that in their study acceptance was considered to play a central role in adjusting to living with ME/CFS. They explained that when individuals recognised a need to move on with their lives accepting ones identity as a person with ME/CFS helped participants to reach a sense of closure. Acceptance of the self as it is, rather than grieving for the self as it was, or once hoped to be, was reported to facilitate adjustment to life with ME/CFS. Specifically, acceptance of the present self was described as leading to realistic goal-setting and a modification of lifestyle. In turn, participants reported regaining a sense of personal control, self-esteem and self-worth (Dickson et al., 2008). Although qualitative studies use small

sample sizes and therefore findings cannot be generalised (Willig, 2008) the data certainly indicates that acceptance serves a helpful role for this population.

Findings in the quantitative literature appear more mixed. Bogaerts et al. (2007) explored acceptance imagery. Participants were asked to imagine four scripts, one of which depicted acceptance of ME/CFS and its consequences. Analysis revealed that when engaging with the acceptance script, individuals showed less hyperventilation and reported less “negative” emotions as well as symptoms such as headaches. Bogaerts et al. (2007) also asked participants to complete an “acceptance of chronic fatigue” measure. Surprisingly, scores on this measure were not found to be related to self-reported symptom complaints or negative/positive affect scores. Perhaps this suggests that acceptance *in action*, i.e. engaging in acceptance imagery, is more influential than a general attitude towards accepting ME/CFS. This hypothesis may be worthy of future investigation.

Only 30 participants took part in the study by Bogaerts et al. (2007) and all of these were female. The generalisability of their findings to other individuals therefore seems questionable. A different study by Brooks, Rimes and Chalder (2011) also looked at acceptance of ME/CFS yet included 259 individuals and had a more balanced gender split. Conversely to Bogaerts et al. (2007), analysis revealed that lack of acceptance was related to higher fatigue and lower physical functioning as well as lower work and social adjustment. Lack of acceptance was also correlated with depression and two facets of perfectionism – concern over mistakes and doubts about actions. As analysis utilised correlations we cannot assume causation (whether lack of acceptance *caused* fatigue, depression, etc). Nevertheless, it could be argued that the connection between them provides rationale for further research into the therapeutic use of acceptance in ME/CFS.

Another two quantitative studies provide mixed findings regarding acceptance and ME/CFS. Poppe et al. (2013) and Eglinton and Chung (2011) both used a measure called the Illness Cognition Questionnaire (Evers et al., 2001), which measures statements relating to illness such as “I have learned to accept the disability of my disease”. It is comprised of three subscales thought to measure cognitions in the categories of “acceptance”, “helplessness”, and “disease benefits”. Poppe et al. (2013) found improvements in acceptance, fatigue, mental-health quality of life and physical-health quality of life after CBT intervention. They did not conduct analysis considering acceptance as a mediator of change, however it could be hypothesised that acceptance mediated the benefits that participants reported. Conversely, Eglinton and Chung (2011) found that acceptance cognitions were not a significant predictor of physical or mental fatigue, or psychological well-being. Although findings considering acceptance and ME/CFS appear mixed this researcher would argue the area is worthy of further investigation.

#### ***1.4 Mechanisms of change within mindfulness and MBI***

It appears many models aiming to elucidate *how* mindfulness elicits change have been proposed in recent years and no one model has been adopted as standard. Some of these (e.g. Van Dam, Hobkirk, Sheppard, Aviles-Andrews & Earleywine, 2013; Penberthy et al., 2013; Birrer, Rothlin & Morgan, 2012; Perich, Manicavasagar, Mitchell & Ball, 2012; Fletcher, Schoendorff & Hayes, 2010) present mechanisms specific to particular interventions and/or presentations whereas others suggest mechanisms pertinent to mindfulness on its own (e.g. Vago & Silbersweig, 2012; Grabovac et al., 2011; Hölzel et al., 2011; Coffey et al., 2010). The present research focusses on mindfulness across interventions. Consistent with this I outline below three models which elucidate active ingredients of change within mindfulness as it stands alone. These models were proposed within the past four years and each provides a different angle from which to understand how

mindfulness brings about change. Following this an overview of elements which individuals have themselves described as pertinent for change within MBIs is presented.

The first model is proposed by Coffey et al. (2010) and provides useful information about how mechanisms could influence each other and the level of impact they are likely to have on individuals' functioning. As mentioned earlier, Coffey et al. (2010) concluded from their analysis that 'mindfulness' embodies two separate factors – "present-centred attention" and "acceptance of experience". Using these factors to predict scores on mental health measures, they concluded that mindfulness impacts mental health both directly, and via its impact on coping mechanisms. Through a factor analysis the mechanisms "clarity about one's internal life", "negative emotion regulation", "non-attachment" (the ability to "view happiness as independent of external circumstances", p. 237) and "rumination" were identified. A path analysis was then used to illuminate relationships between the mechanisms.

Coffey et al. (2010) found that when participants were more accepting of their internal experience they became clearer about their feelings and better managed difficult emotions. Analysis revealed that this fed into better mental health, measured by the constructs "psychological distress" and "flourishing mental health". Flourishing was defined as "a sense that one is living a rich and satisfying life" (p. 253). They also found that participants became clearer about their feelings when they paid significant attention to their present experience. Again, this contributed to better mental health. According to analysis, in both cases being clear about feelings also led participants to ruminate less which, in turn, connected to flourishing.

In both of these studies analysis revealed that although both attention and acceptance impacted upon change mechanisms, acceptance exerted much stronger effects, suggesting that acceptance may impact well-being to a greater

extent than attention (Coffey et al., 2010). Another noteworthy finding was that attention both decreased *and increased* levels of psychological distress. This was interpreted by suggesting that heightened attention may have amplified participants' awareness of distress thus increased scores, at the same time that this increased awareness lead to better management of internal experiences and thus reduced scores. Analysis also revealed interesting results regarding non-attachment which significantly predicted flourishing but not distress. Perhaps this indicates that many participants flourished when assuming an attitude of non-attachment yet were unlikely to become distressed if attached to objects and outcomes they desired.

Since Coffey et al. (2010) conducted comprehensive analyses to establish distinct constructs and map their relationships to one another, using this model to understand mindfulness and its mechanisms is a credible decision. Their model was reported to explain 54% of the variance in flourishing and 60% of the variance in psychological distress. Their findings therefore appear informative and carry helpful implications for practice. Despite this approximately 40% of variance was not accounted for perhaps indicating that other unidentified change mechanisms were also at work. Moreover, although Coffey et al. (2010) provide a good understanding of the constructs involved in change, how they relate to one another and their impact on mental health, they do not focus on the nuances of the immediate process. In the interest of providing a fuller picture therefore, the following model proposed by Grabovac et al. (2011) will be illuminated.

Grabovac et al. (2011) propose the Buddhist Psychological Model (BPM), which does explore the nuances of the immediate process. They state that mindfulness elicits change by interrupting "mental proliferation". According to Grabovac et al. (2011) mental proliferation occurs when a series of mental events (thoughts, images, judgements, etc) are triggered by an initial mental event or "sense impression". The initial mental event or sense impression is the cognitive or bodily

response a person experiences when encountering new stimuli. When a person experiences this cognitive or bodily reaction two processes are typically activated: further cognitive reactions (e.g. thoughts) to the initial cognitive or bodily response and a judgement of the initial response as pleasant, unpleasant or neutral. Grabovac et al. (2011) argue that humans habitually respond to pleasant experiences with attachment and unpleasant experiences with aversion, working to prolong the pleasant and eliminate the unpleasant. We also experience a reaction to our initial reaction to the cognitive or bodily response, i.e. we have thoughts and feelings about our thoughts and feelings. As before, we judge these as pleasant, unpleasant or neutral, attaching ourselves to the pleasant and wanting to avoid the unpleasant. Again we experience thought and feeling reactions to the latest thoughts and feelings. As long as we experience them as pleasant or unpleasant and work to attach or avoid the train of thought continues. It is this that Grabovac et al. (2011) refer to as “mental proliferation”. If we repeatedly judge thoughts and feelings as unpleasant and aversive an unwanted train of thought is likely to continue.<sup>2</sup>

According to the BPM both a mindful attitude and mindfulness practice interrupt mental proliferation. This is thought to occur through the focussing of attention. The BPM posits that only one object can be held in attention at one time and thus activities which switch attention, such as mindfulness, interrupt the mental proliferation process. According to Grabovac et al. (2011) the most common forms of mindfulness practice referenced in the literature are “insight practice” and “concentration practice”. Each is thought to focus attention in different ways. The

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<sup>2</sup> Cognitive-behavioural literature might term attachment to a train of unpleasant thoughts as ‘catastrophising’ or ‘rumination’ (e.g. Centre for Clinical Interventions, n.d; Nolen-Hoeksema, Wisco & Lyubomirsky, 2008).

first, insight practice, involves attempting to observe three characteristics in experience: impermanence, suffering and 'not-self' (explained further in Grabovac et al., 2011). The second, concentration practice, involves focussing attention solely on one object, usually thoughts or one of the five senses. According to Grabovac et al. (2011) engaging frequently in both or either practice often leads to long-term reductions in habitual attachment and aversion reactions. This is thought to consequently decrease the regularity of mental proliferation. In other words, mindfulness practice can reduce how frequently we engage in distressing thought patterns.

Neither Coffey et al. (2010) nor Grabovac et al. (2011) explain how the mechanisms they identify map onto neurocognitive processes. A growing body of neuro-imaging literature provides evidence that mindfulness can modulate and produce lasting changes in the brain (Vago & Silbersweig, 2012; Hölzel et al., 2011). Therefore to present a well-rounded account of how mindfulness may effect change it may be important to illustrate a model which maps the phenomenological experience of change onto brain activity. Vago and Silbersweig (2012) provide a thorough and comprehensive framework and present much research to support the connections drawn within their model.

The model is called 'S-ART' which stands for 'self-awareness', 'self-regulation' and 'self transcendence'; umbrella terms which Vago and Silbersweig (2012) argue can be influenced and increased through mindfulness training. The mindfulness practices it focuses upon include the concentration and insight practices described in Grabovac et al. (2011) as well as another, "ethical enhancement practice", which involves cultivating compassion and kindness towards oneself and others. Similar to Grabovac et al. (2011), the model is based on the assumption that cognitions and emotions are often distorted or biased. Consistent with Grabovac et al. (2011), Vago and Silbersweig (2012) hold that individuals have a tendency to automatically

experience stimuli as attractive, aversive or neutral and to process stimuli experienced as attractive or aversive differently to that experienced as neutral.

Vago and Silbersweig (2012) expand the theory further by explaining the processes behind how stimuli are registered and evaluated. They argue that our initial attentional resources respond to stimuli based on how phenomena are currently represented in our brains, i.e. our current understanding of them. What our brains pay attention to, whether stimuli in the outside world or internal stimuli such as emotions and cognitions, is therefore a result of not just the stimulus but our existing understanding of it and how we see ourselves in relation to it. In this sense our attention is 'biased'. Vago and Silbersweig (2012) argue this bias causes distress because, over time, dedicating attentional resources to stimuli we wish to enhance or get rid of can become habitual, suffused with personal meaning and relevance, and can dictate our behaviour. In other words, we process stimuli in a biased manner according to how we understand the world and in doing so create a distorted construction of our experiences which feed back into and cement our existing understandings. Some of these understandings cause us distress.

The S-ART framework also goes further than Grabovac et al. (2011) in explaining how the impact of mindfulness on attention manifests over time. It proposes that mindfulness practice can 'undo' cycles of embedded attitudes towards the self and the world by modulating three self-processing systems - the enactive experiential self (EES), the experiential phenomenological self (EPS) and the evaluative narrative self (NS). The EES refers to the processing of sensory and affective stimuli through motor mechanisms which are not conscious. The EPS refers to the processing of conscious present-moment awareness. The NS refers to evaluative processing of the self, dependent upon one's existing narratives about the self/world. According to Vago and Silbersweig (2012) mindfulness practice improves the integration and efficiency of these systems.

Vago and Silbersweig (2012) say mindfulness does this via six processes - intention and motivation (to practice), regulation of attention, regulation of emotion, extinction (of behaviours which prevent happiness and flourishing) and re-consolidation (of new information into one's self-narrative), pro-sociality (voluntary action taken to benefit others), non-attachment and de-centering (stepping outside one's immediate experience and taking an observer perspective). They provide an in-depth exploration of how each process relates to each other and to neurocognitive change. Briefly outlined, the six processes work through the fronto-parietal control system - the system in the brain responsible for integrating information from the EES, EPS and NS processing systems and also responsible for plasticity amongst these networks (Vago & Silbersweig, 2012). Similar to how Coffey et al. (2010) and Grabovac et al. (2011) suggest mindfulness effects well-being, Vago and Silbersweig (2012) argue that, as a result of this improved efficiency and integration, individuals experience a reduction in distressing cognitions and emotions and a reduction in attachments to thoughts and feelings. They suggest also that this improved efficiency and integration results in an increase in pro-social dispositions such as compassion and forgiveness towards self and others and a removal of biases inherent in habitual forms of cognition. Further exploration of how each process maps onto the brain is beyond the remit of this research and unwarranted in a counselling psychology study. Readers may find that Hölzel et al. (2011) provide a more accessible, although slightly less recent, description of how potential mechanisms map onto the brain.

It may be interesting to note that change through mindfulness can be seen as a sequential endeavour. Indeed, Coffey et al. (2010) indicate this may be the case with their path analysis focus. Similarly, Hölzel et al. (2011) highlight that individuals need the ability to focus attention to engage in exercises, rather than drift into daydreaming. This perhaps suggests that focussing attention successfully provides

a foundation from which meditators can benefit from other mechanisms (Hölzel et al., 2011). It appears such knowledge has been implicitly held for years in Buddhist and Indian yogic traditions. Hölzel et al. (2011) highlight that such traditions often recommend types of focused attention practice before moving to other meditations such as insight and compassion practices.

This researcher is unaware of any qualitative literature exploring mechanisms of change pertinent to MBIs in a sample of individuals with ME/CFS. However, studies have been conducted in other samples and, from this, individuals themselves have highlighted elements pertinent to the change process. The literature here is too expansive to provide a detailed review of each study. Instead, the following will detail five areas: cognitive patterns, relationship to self, relationship with teacher, experience of the group and relationship to home practice.

Changes in cognitive activity appeared a salient aspect of the MBI experience in every paper reviewed. Interventions were understood to increase awareness of cognitions. Such awareness was perceived as giving participants choice in how they responded to their present experience, including their cognitions, feelings, bodily sensations and current environment (e.g. Bihari & Mullan, 2014; Surawy, McManus, Muse & Williams, 2014; Felton et al., 2013; Irving et al., 2014; Morone, Lynch, Losasso, Liebe & Greco, 2011; Langdon, Jones, Hutton & Holttum, 2011; and Malpass et al. 2011). The choices available were described as accepting the experience (e.g. Surawy et al., 2014), focussing on less upsetting stimuli (e.g. Felton et al., 2013; Morone et al., 2011) and changing what one could about both the present situation and one's behavioural responses to it (Bihari & Mullan, 2014; Irving et al., 2014; Morone et al., 2011; Langdon et al., 2011). The benefits which were reported from becoming aware of and making different choices were less disruption in life (Surawy et al., 2014), less personal distress and fewer arguments with others (Bihari & Mullan, 2014).

Many studies described changes in individuals' self-relationships due to mindfulness intervention. Participants described mindfulness as becoming part of them, as understanding themselves better, as being more connected with themselves, being more confident, being more self-compassionate and taking better care of themselves (Bihari & Mullan, 2014; Irving et al., 2014; Surawy et al., 2014; Felton et al., 2013; Hopkins & Kuyken, 2012; Morone et al., 2011; Langdon et al., 2011). Participants described these changes occurring through a variety of mechanisms, including learning about the self and one's automatic reactions, focussing on and becoming aware of sensations not previously noticed, relating 'mindfully' to both pleasant and unpleasant experiences, considering the self compassionately, forgiving the self and being less judgemental of the self (Bihari & Mullan, 2014; Irving et al., 2014; Surawy et al., 2014; Felton et al., 2013; Hopkins & Kuyken, 2012; Morone et al., 2011; Langdon et al., 2011).

Other studies described the conduct of the facilitator as a significant contributor to change processes in MBIs. This appears to go beyond their obvious contribution - the organisation of groups and presentation of course materials. Facilitators appeared able to influence changes by the creation of a particular environment. Facilitators were particularly credited with creating a sense of safety around meditation and encouraging a compassionate space. The way the facilitator spoke and used language was noted to influence the environment and individuals' engagement. Gentle encouragement, normalising, and communication of understanding were also perceived to influence change. Moreover, many considered it important that facilitators practised meditation themselves and could therefore be used as role-models to learn from (Irving et al., 2014; Surawy et al., 2014; Lauricella, 2013; van Aalderen, Breukers, Reuzel & Speckens, 2014; Hopkins & Kuyken, 2012).

Another facet appearing important to change was the experience of being in a group. Participants frequently spoke about the motivating nature of the group. For example, Irving et al. (2014) and van Aalderen et al. (2014) described the group as a motivating factor to persevere with the course. Similarly, participants in Hopkins and Kuyken (2012) expressed that knowing they would see the group again motivated them to attend reunions. Individuals in Lauricella (2013) reported they were less distracted from practice in a group setting. Participants in Lauricella (2013) and Langdon et al. (2011) noted a sense of accountability to the group which motivated them to practice in session and at home. Similarly, participants in Langdon et al. (2011) explained that meeting with the group reminded them of the value of mindfulness which encouraged engagement in home exercises. The group was also found to aid reflection on practice (van Aalderen et al., 2014), and from such discussions individuals reported learning ways to overcome challenges in this (Irving et al., 2014; Hopkins & Kuyken, 2012).

Other changes participants noted as being influenced by the group were personal growth (Irving et al., 2014) and becoming more accepting of one's difficulties and struggles (Irving et al., 2014; Surawy et al., 2014). It appeared that gaining support from the group, for example encouragement (Surawy et al., 2014) and normalisation (Irving et al., 2014), played a key part in such development.

The final facet appearing notable for change was individuals' relationships to home practice. Home practice appeared to be perceived by many as important for increased and/or continued benefit (e.g. Langdon et al., 2011). Many studies reported individuals finding themselves either struggling or reticent to engage in home practice (e.g. de Zoysa et al., 2014; Langdon et al., 2011), and suggested that various facets can be helpful in this area. In three studies, participants reported changing how they practice to overcome barriers. The most common adaptation was shortening practice (e.g. Irving et al., 2014; Surawy et al., 2014; Langdon et al.,

2011). Another was using mindfulness in more informal ways, for example to cope with stressful situations in situ or enhance pleasant experiences (de Zoysa et al., 2014). Participants in Langdon et al. (2011) reported that knowing lapses were normal and treating themselves gently helped re-engagement. Also, feeling nothing else was available, e.g. social support, was reported to help re-engagement, as was experiencing negative feelings mindfulness had previously helped with (Langdon et al., 2011). Setting aside time and space was found beneficial, as was symbolically marking a particular area for practice (Langdon et al., 2011). Participants in Hopkins and Kuyken (2012) and Langdon et al. (2011) reported refresher and reunion sessions were also helpful to re-engage in practice.

### ***1.5 Rationale for the current research***

As evidenced above, the literature presently demonstrates a relatively good understanding of the changes that MBIs can elicit in a range of populations, and the mechanisms through which these are achieved. It shows also some understanding of the changes MBIs can elicit in an ME/CFS population. However, we have very little understanding of what it is like to engage in an MBI if one lives with ME/CFS.

This area is worthy of investigation for many reasons. First, as highlighted earlier, preliminary studies suggest mindfulness has been found helpful for anxiety, depression, physical functioning, fatigue, somatisation, phobic anxiety, paranoid ideation, obsessive-compulsiveness, interpersonal sensitivity, psychotic responses, 'unhelpful' beliefs about emotions, catastrophic thinking, 'boom and bust' behaviour, self-compassion and general impairment, in samples with ME/CFS. It has also been found helpful for difficulties that people with ME/CFS experience (pain, fatigue, cognitive dysfunction, digestive problems, headaches/migraines, sleep difficulties, stress, anxiety, depression, poor quality of life, 'boom and bust' behaviour, identity and self-relationship issues) in other populations. Therefore, it is arguable that any research in this area appears a worthwhile endeavour.

Secondly, a lack of research into how people with ME/CFS experience MBIs means that health-care practitioners are less able to engage in ethical practice. Governing bodies such as the British Psychological Society [BPS] and the Health and Care Professions Council state that to work ethically, professionals must provide interventions embedded within an evidence base. This is stated frequently throughout their publications and websites. An evidence-base is founded upon research and one is lacking in this area.

Thirdly, there appears a paucity of information which can be meaningfully used to guide therapeutic intervention. It is reasonable to presume that having ME/CFS impacts engagement in MBIs, and/or their potential utility. For example, limited energy and the necessity for energy management might impact engagement with home-practice. Difficulties with word-finding or concentration might negate one's ability to contribute to group discussions. Although research into ME/CFS has utilised measures of 'acceptance', these are not inclusive or flexible enough to provide a clear picture of if, or how, living with ME/CFS impacts the MBI experience. Similarly, although useful in other capacities, data which tells us MBI 'decreases anxiety and depression', 'increases physical functioning and quality of life', and 'improves 'boom and bust' behaviour', for example, tells us little about what these processes mean to someone. It seems important to understand such nuances so professionals can design interventions, and utilise their skills, to best effect.

### ***1.6 Focus of the current research***

The current research asked "How are mindfulness based interventions experienced by people with ME/CFS?" and hoped to illustrate the nuances of such an experience. To do so, the current study utilised a qualitative methodology. As explained by Willig (2008) and Langdridge (2007), quantitative research assumes that objective knowledge can be produced, concerning itself with counting some phenomenon or aspect thereof to either prove or disprove a theory. Qualitative

research takes a different focus, aiming to understand how people make sense of the world and experience particular phenomena. The objective, rather than prediction, is describing and sometimes explaining events and experiences.

As alluded to earlier, the measures used in quantitative data - for example questionnaires - are chosen by the researcher and therefore shaped to a large extent by them. The data they generate is restricted by limited response options and the prohibition of spontaneous responses. Conversely, qualitative approaches are more participant-led. Response-options are far greater; allowing for unanticipated data to emerge and a more complex understanding of phenomena under investigation. Qualitative approaches are therefore particularly useful for giving participants a voice, and allow us to learn about phenomena from the perspective of the individual experiencing it.

## **2. Methodology**

This chapter discusses several qualitative methods in depth and briefly outlines those available to researchers. Interpretative Phenomenological Analysis (IPA – Smith, 1996) was chosen to analyse the current data and this methodology and its underlying epistemology is thoroughly explored. My personal views regarding ontology, epistemology, and the role I understand myself to take as a researcher are then discussed.

The narrative moves on to relaying the practical details of the research, discussing the body-focus incorporated into analysis, the analytic process, sample, recruitment procedure and demographic questionnaire. The process from initial contact to interview is described, as are general ethical considerations, the question schedule, pilot interviews and recording equipment. How the main interviews were conducted is outlined, the debriefing process explained and credibility and further ethical considerations of the study discussed. The chapter concludes with a section dedicated to reflexivity.

### ***2.1 Research aim***

As explained earlier, the current study aimed to illuminate the phenomenon of engaging in MBIs whilst living with ME/CFS. The research hoped to access what this was like for participants through the nuances of their behavioural, affective, and cognitive experiences and the meanings individuals attached to these. It was hoped that the research would provide insights which were educative for both professionals and other interested parties. Such insights were anticipated to illuminate helpful and unhelpful aspects of the interventions, providing information about why this was found to be the case. It was hoped that the knowledge generated might help guide the development of future interventions, as well as contribute to an evidence base regarding ME/CFS and MBIs.

## **2.2 Qualitative methods of analysis**

There are a number of qualitative methods available. As explained by Smith, Flowers and Larkin (2009), each suggests a different understanding of what constitutes data, what researchers can infer from data and what analysis can achieve.

Three commonly used qualitative approaches – grounded theory, discourse analysis, and narrative analysis, were not chosen to analyse the current data. There were two main reasons for this. First, it was thought that the epistemological foundations of some methods were incompatible with the researcher's personal philosophical beliefs.<sup>3</sup> Second, it was believed that their analytic aims were unsuited to what the current research hoped to achieve.

Grounded theory was originally developed with a realist ontology, although other versions of the method, for example a social constructionist version, have been devised (Willig, 2008).<sup>4</sup> According to Willig (2008), traditional grounded theory “assumes that social events and processes have an objective reality in the sense that they take place irrespective of the researcher and that they can be observed and documented by the researcher” (p. 48) (a realist perspective). However, grounded theory also supposes that a person's interpretation of events shapes what consequently occurs in the world. Hence, grounded theory is taken away from a purely realist perspective and instead adopts a “symbolic interactionist perspective” (Willig, 2008, p. 48). Although grounded theory's epistemology appears somewhat similar to the current study's positioning (critical realist), it seems to differ in one major aspect. Traditional grounded theory appears to assume that the researcher acts as a witness who is able to represent a clear picture of what is going on,

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<sup>3</sup> 'Epistemology' refers to the assumptions a person makes regarding how knowledge can be known.

<sup>4</sup> 'Ontology' refers to the assumptions a person makes regarding what knowledge can be known.

without their own assumptions or expectations affecting the analysis (Willig, 2008). As explored later, I would argue that qualitative analysis is always conducted through the lens of the researcher and thus cannot be separated in this manner.

Furthermore, the aims of grounded theory appeared mismatched to the hopes of the current study. According to Willig (2008), grounded theory aims to produce a theory or number of theories. Since the aim of the current research was to explore experience rather than generate a theory, grounded theory was deemed unsuitable.

Discourse analysis holds a social constructionist epistemology and therefore lies on the opposite end of the spectrum to realist methods; instead it is understood as a 'relativist' methodology (Willig, 2008). Willig (2008) explains that discourse analysis assumes we cannot produce knowledge about the nature of a phenomenon. Since the current research aimed to do just this – to explore what MBIs are like when one is living with ME/CFS – discourse analysis was considered philosophically incompatible with the present focus. Moreover, as explained by Willig (2008), discourse analysis tends to focus upon either what discursive resources are available to individuals and the impact of this availability, or what people *do* with language. Again, this focus was considered irrelevant to the current study.

Narrative analysis developed from social constructionism. Despite this, narrative approaches span a wide range and have been integrated with aspects of grounded theory, discursive psychology and phenomenology (Willig, 2008). Phenomenology refers to a branch of philosophy concerned with what being human is like and what is important to us, known as our 'lived experience'. This focus on lived experience was initially written about by Husserl (1859-1938) who famously argued that we should aim to 'go back to the things themselves' (Smith et al., 2009). Since narrative analysis can take a phenomenological focus similar to IPA, it was considered for use in this study. However, although narrative analysis does focus on

the content of peoples' stories it also focuses on constraints and opportunities and what narratives are available to particular individuals or groups of individuals. As the current study was not looking to assess such power imbalances or explore the impacts of wider cultural narratives, such a focus was thought unnecessary and potentially detrimental to the primary aim – to elucidate experience.

Thematic analysis was also briefly considered for the current study. This methodology appears to fall into two camps – as a tool used across analytic methods and as a method of analysis in its own right (Braun & Clarke, 2006). Braun and Clarke (2006) explain that thematic analysis in the second instance does not stem from a particular epistemological or theoretical positioning. Therefore the method can be applied across a range of positions, being compatible with both the realist and relativist ends of the spectrum and those philosophies which fall in-between.<sup>5</sup> Thematic analysis would therefore have been appropriate to my critical realist position and for the current study.

### ***2.3 IPA, phenomenology, hermeneutics, and ideography***

Rather than thematic analysis, IPA was chosen due to its strong phenomenological commitment and its standpoint on interpretation. According to Smith et al. (2009), Smith developed IPA as a method which focussed specifically on experiential and qualitative aspects because he felt these had been somewhat lost in other available qualitative methods. IPA's primary aim is to elucidate phenomena and this method was therefore felt most appropriate for the current endeavour. IPA also has strong philosophical roots embedded within hermeneutics, the study of interpretation, holding that no knowledge can be known outside of interpretation (Smith et al., 2009). This philosophy is consistent with my personal beliefs (as discussed later) and thus was again thought particularly relevant for the current study. The

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<sup>5</sup> These 'in-between' philosophies are often referred to as 'contextualist' standpoints (Braun & Clarke, 2006).

philosophies underpinning IPA and their contribution to the methodology are discussed below.

Since IPA is committed to describing experience in its own terms, it has been heavily influenced by the work of Husserl. First, as mentioned earlier, Husserl placed great emphasis on paying attention to the nuances of objects. IPA shares this focus, being committed to illuminating the intricacies of experiences as best researchers can (Smith et al., 2009). Second, Husserl said that humans naturally fit experience into pre-existing categories and argued that to really comprehend phenomena we need to focus on each thing in its own right. He suggested we switch our attention from the object to our perception of it, consequently recognising and putting aside (bracketing) our assumptions so we can see the object in a new light. Husserl called this process 'eidetic reduction'. In light of Husserl's theories, bracketing is considered a fundamental process within IPA (Smith et al., 2009).

We can see in Smith et al. (2009) that interpretation has been thoroughly considered in the development of IPA which, as mentioned earlier, views phenomenological investigation as a fundamentally interpretative process. IPA holds that factors such as relationships, language, time, past experiences, our bodies, and the presence or absence of objects, influence the lens through which we gain understanding of the world. IPA says that the findings presented in research write-ups are the product of a 'double hermeneutic', passing through two lenses of interpretation – that of the participant and the researcher. Different philosophers have written about what they believe influences the interpretative lens – the 'hermeneutics' we perceive the world through (Smith et al., 2009). Those considered pertinent to the current study are described below.

The work of Heidegger (1889-1976) has been particularly influential in IPA's development. Heidegger was a student of Husserl's and branched out from him,

doubting whether any knowledge could exist separate to that which is interpreted. Heidegger concerned himself with 'Dasein', meaning 'there-being', considering what can be known as a human being in the world. He argued that interpretation is fundamentally bound with the world, and with death, which he said imposes the concept of time on individuals (Smith et al., 2009). Smith et al. (2009) explain that it was from Heidegger's work that IPA took the idea that research findings are always an interpretation influenced by objects, relationships, language, and time.

As explained by Smith et al. (2009), Heidegger also asserted that interpretation is dependent upon our fore-conception, our experiences, expectations and presumptions about the thing we are experiencing. Similar to Husserl, Heidegger argued that when conducting phenomenological enquiry, we should prioritise the new thing, rather than the fore-conception. In contrast to Husserl, Heidegger said that priority can never be fully given to the new object because the fore-conception is needed to recognise and understand it. He elaborated that similar to the fore-conception shaping an individual's reading of an object, the object will also shape the fore-conception, as engaging with the object tells the individual which parts of their fore-conception are needed to make sense of it. Smith et al. (2009) explain that IPA's understanding of bracketing has been shaped by this work, being seen as a cyclical process which can never be fully achieved.

The work of Merleau-Ponty (1908-1961) has also been pertinent to IPA's development. Similar to Heidegger, Merleau-Ponty emphasised that what we know about the world is always through interpretation and that understanding is always unique to the interpreter. Merleau-Ponty spoke about 'embodiment' - the role of the body in interpretation. He said that humans always interpret others through knowledge of their own bodies and used the term 'body-subject' to refer to humans as interpreters in this way. Smith et al. (2009) explain that different IPA researchers prioritise bodily experience to varying degrees. It appears that some, for example

Finlay (2006), argue for a pronounced consideration, e.g. the observation, understanding, and interpreting of gestures, whereas others (e.g. Smith et al., 2009) incorporate body-focus in a more subtle and understated way. As the reader will see, the current research adhered to a more pronounced consideration, incorporating a 'body-focus' into the analytic process. IPA's consideration of the body in interpretation was therefore thought particularly relevant to the present study.

IPA's conceptualisation of interpretation is further informed by Sartre (1905-1980). Sartre said that what is absent is as important for the process of interpretation as that which is present. He argued that when something absent becomes present, or when something expected to be present is absent, individuals' interpretations of their experience changes (Smith et al., 2009). According to Smith et al. (2009), Sartre wrote in particular about the absence or presence of people, extending Heidegger's focus on the world to considering social and personal relationships. IPA takes from Sartre the idea that interpretation is contingent on one's relationships to other humans and their presence or absence.

The writings of Schleiermacher (1768-1834) also facilitated the development of IPA. Schleiermacher said that if one gains an understanding of a text, they also gain an understanding of the author, one which can supersede the understanding the author has of themselves. IPA takes from this the premise that a thorough analysis can offer insights which go beyond obvious surface level claims of participants (Smith et al., 2009). This appears useful for psychological researchers as we are allowed to consider more understandings of our data, from which we can gain richer insight and ultimately more benefit for our field and clients.

The concept of the 'hermeneutic circle' is also thought influential to IPA's development. This concept runs through the writings of many philosophers and

refers to a connection between part and whole objects and the relationship between them. Essentially, the premise of the circle is that understanding a whole is dependent on understanding its parts and vice versa (Smith et al., 2009). Smith et al. (2009) give the example of words and a sentence; the meaning of a word only becoming apparent in the context of the whole sentence, yet the sentence being made up of individual words with unique meanings. The concept of the hermeneutic circle influenced Smith to develop IPA as an iterative process. Rather than a series of linear steps, analysis is a process where the researcher goes back and forth between the parts and the whole, viewing the text from a variety of vantage points (Smith et al., 2009).

To further understand IPA, it can be helpful to consider the debate between ideographic and nomothetic research and where IPA positions itself within this. The term ideography was coined by Wilhelm Windelband (1848-1915) and refers to research committed to describing and understanding the particular (Robson, 2011). The ideographic approach is thought to have developed in response to the 'nomothetic' approach, a way of researching which has come to represent large sample sizes and a search for general laws of behaviour at a group or population level (Robson, 2011; Smith et al., 2009). Nomothetic research is highly criticised by those who argue that probable group norms are arbitrary and misrepresentative of the individual (see Smith et al., 2009, p. 30, for examples). IPA, with its focus on analysing data in depth and on understanding how phenomena are experienced by certain people in certain contexts, obligates itself to an ideographic viewpoint (Smith et al., 2009).

Essentially, IPA was chosen to answer the current research question not just because it aims to examine the life world in detail, but also because its focus on interpretation was felt compatible with my ontological and epistemological beliefs. These beliefs are expanded on in the next section.

## ***2.4 Ontology, epistemology, and the role of researcher: Myself as a critical realist***

As noted earlier, when aiming to produce knowledge, we make assumptions about what can be known (ontology) and how it can be known (epistemology). Ontological and epistemological positions can fall into or between one of the two categories mentioned earlier; realism or relativism, with the naïve realist saying it is possible to generate knowledge of the world as it really is and the radical relativist holding that knowledge of the world as it really is does not exist. As noted before, those whose philosophies fall in-between are considered 'contextualist' (Willig, 2008).

IPA makes no claims about what is 'true' or 'false' and does not engage in the debate of whether a person's perception of an event corresponds to an external reality. In this sense, IPA does not engage with the realist-relativist epistemological and ontological dialogue (Willig, 2008). However, Willig (2008) explains that IPA can fall into both realist and relativist camps. On one hand, IPA assumes that inner experiences such as thoughts and sensations exist, that the phenomenon under investigation exists and that researchers can find out about these by asking. Conversely, IPA is primarily concerned with individuals' subjective experience. As we have seen, it prioritises interpretation as central in the analytic endeavour and assumes that different individuals can experience the same phenomenon in radically different ways (Smith et al., 2009; Willig, 2008).

My personal ontological beliefs are that truth exists, that there is a world out there which exists. I believe we can generate some idea of what this world might be like. In this sense I am a realist. However, my epistemological standpoint is that what is 'out there' cannot ever be fully and directly accessed. I do not believe humans can be consciously aware of everything they experience and I think each person has a unique lens shaping their interpretation of the world. Thus, my personal view is what is 'out there' is only somewhat accessible to individuals, and consistent with the

double hermeneutic, is filtered through both the lens of the participant and the lens of the researcher. This is not to say the end result is arbitrary, but that it is improbably 'the whole truth and nothing but the truth'. I therefore take a critical realist position. Since IPA suggests that we can find out about phenomena through investigation, and suggests that analysis is inherently an interpretative process, it seems to be compatible with this critical realist standpoint.

Willig (2008) suggests that it is important to understand how methods position the researcher and also how researchers understand themselves. She says realist methods understand researchers as unearthing findings whereas relativist methods perceive researchers as co-constructing findings. Willig (2008) suggests that in IPA the researcher is both a witness and constructor; but the witness role appears more explicit. For example, the witness role is demonstrated within the terminology IPA uses - themes are said to 'emerge' and categories 'identified'. Contrastingly, the constructor role, although inherent in the research process, is not built into language as in other methodologies like discourse analysis (Willig, 2008). Consistent with IPA, I understand myself as both a witness and co-constructor, finding out about phenomena whilst inevitably shaping what and how this can be known. This identity appears consistent with a critical realist standpoint.

## ***2.5 Analytic method and procedure***

Smith et al. (2009) encourage researchers to adjust IPA according to their wishes, epistemological and ontological positions and research topic. They suggest novice researchers follow the guidelines in their book, adapting these when and where they feel comfortable and when they believe the data requires it. Their directions made sense and, easily imagining the steps a researcher would take during analysis, it was decided to follow their framework using it as the foundation to the analytic method.

It was decided to build upon this basis by introducing a specific present-focussed awareness of the body into the analysis. By body, all sensory and cognitive experiences, particularly thoughts and sensations, was meant. The reasons for this choice were numerous. First, present-focused awareness, as a fundamental facet of mindfulness, is at the heart of the current research. Incorporating such awareness into analysis felt respectful and appropriate. Second, consistent with Merleau-Ponty, I believe what is known by individuals, and therefore researchers, is strongly influenced by the body. For me, the process of understanding another's experience is a process of creating an experience within oneself we believe approximates the other, based on our previous knowledge and history. As the body was thought integral to understanding others' experience, again it felt suitable to incorporate explicit body-focus into analysis.

Third, it was found that explicit body-focus generated a different and deeper analysis. Rather than focusing solely on what transcripts and recordings meant to me cognitively, attention was paid to what they meant experientially which had the implication of new insights being obtained. Fourth, explicit present-focused awareness was found to assist bracketing. As argued by Husserl and Heidegger, and by Grabovac et al. (2011) as described in chapter one, bringing present cognitions into conscious awareness affords the ability to step back from them. Repeatedly bringing awareness to my thinking allowed me to recognise preconceptions and assumptions better, thus increasing my ability to put these aside. It was felt that extra assistance in bracketing would be particularly beneficial for the current research due to my background in mindfulness and ME/CFS. My mother has lived with the condition for many years, developing symptoms when I was three years old. The illness has therefore been embedded within my way of life and it seems I have developed a strong and complex belief system pertaining to it. I also practice mindfulness regularly and use ACT as my main therapeutic model.

As noted above, IPA believes that the researcher cannot be separated from their results and will produce *an* interpretation rather than *the* interpretation of phenomena (Willig, 2012; Smith et al., 2009). Therefore, being particularly engaged with the research topic before investigating it is not considered unacceptable. However, it is thought that a better analysis is produced when researchers are able to consider their data from a multi-faceted viewpoint, a process assisted by bracketing (Smith et al., 2009). Furthermore, as will be discussed later, Willig (2012) argues that the more reflexive and aware the researcher is, the more ethical their interpretation of participants' experiences will be. Since the aforementioned body-focus was found to assist reflection and bracketing, it was felt particularly useful for *me* carrying out *this* research.

Each interview was transcribed by me, not just words being noted but also pauses in speech, laughter and false starts. Paying attention to paralanguage was hoped to capture the essence of the interaction better. Identifying data was changed at this stage to maintain anonymity. Transcripts have been kept securely on my laptop/dropbox, protected by three passwords.

In practice, the first analytic step was reading and re-reading the transcript whilst listening to the recording. I paused frequently to record any initial and/or striking observations, also noting any powerful recollections of the interview. The interview structure was considered; especially whether any narratives bound sections together and particularly rich and detailed sections were highlighted as well as contradictions and paradoxes. Consistent with the body-focus, deliberate attention was paid to powerful or noteworthy sensations and time spent exploring what these might mean.

The second step involved making in-depth and thorough notes about the transcript. Specific phenomena which participants appeared concerned with were highlighted

and considered. The following questions were deliberated: 'What relationships, processes, places, events, values and principles in this line of transcript matter?', 'What are these like for the participant?', 'How/why is the participant concerned with them?' and 'What does this word/phrase/sentence mean to me?' (Smith et al., 2009). With each answer attention was brought to the body, noticing whether an answer felt 'right' or not. Answers were continually generated until one was found which 'fitted'. The procedure was informed by Gendlin (2003) who has written extensively about this 'focussing' process and Finlay (2006) who encourages researchers to utilise their bodies during analysis. Comments were split into descriptive, linguistic and conceptual paradigms. Analysing each one separately was initially attempted. However, this approach was found to lose certain thoughts and essences. Analysing each line using the different paradigms in chronological order was therefore settled upon.

The third step involved developing emergent themes. Working primarily with the notes rather than the transcript, I aimed to reduce the volume of detail whilst maintaining complexity. Smith et al. (2009) describe a theme as "a concise and pithy statement of what was important in the various comments attached to a piece of transcript" (p. 92). They say that themes capture the psychological spirit of the data, are specific enough to be grounded and abstract enough to be conceptual and encapsulate what is important at that moment (Smith et al., 2009). Consistent with the critical realist stance, it was hoped that some essence of the phenomena would be captured through the emergent themes I generated. During this step, a dictionary and thesaurus were frequently consulted. This enabled me to access different viewpoints on the participant's data and find words which accurately captured what was felt to be the essence of the experience.

A fourth stage, not included in Smith et al. (2009), and which rose organically from the aforementioned process, was added. This was listening to the recording whilst

reading through emergent themes and noticing whether themes matched the essence felt from the recording. As noted above, such a process appears similar to 'focussing' (see Madison, 2014, for a practice example) whereby person B repeats words person A has articulated then person A reconsiders whether these words 'fit' with what they find their experience to be. Consistent with the focussing agenda, any incongruent or uncomfortable words were changed for more meaningful ones. This process felt warranted because it allowed me to represent the life-world found in participants' accounts more accurately. Refer to Appendix B for an extract of transcript analysed to this stage.

All interviews were analysed for emergent themes before continuing to the next stage. Consistent with Smith et al. (2009), the next step involved taking each interview individually and printing out the emergent themes and their accompanying quotes onto smaller pieces of paper. Similarities between them were considered and a process of clustering the emergent themes into superordinate ones ensued. Like-for-like were clustered together and at times emergent themes were considered better placed as superordinate ones. Key events were considered in the grouping as was the frequency in which emergent themes arose. Themes were also clustered according to what the researcher imagined participants were trying to achieve by their narrative. These processes are described as 'abstraction', 'subsumption', 'numeration' and 'function' by Smith et al. (2009). Themes which appeared irrelevant were gradually discarded (Smith et al., 2009). Once clusters had been created, a table of themes was generated for each participant. The overall aim of the stage was to produce "a structure which allow[ed] [me] to point out all of the most interesting and important aspects of [my] participant's account" (Smith et al., 2009, p. 96).

In accordance with Smith et al. (2009), tables of themes were then considered against each other and connections between them investigated. A final table of

themes was created and from this an initial draft of the findings written. Smith et al. (2009) explain that it is common practice to include this final table of themes in the write-up. However, they and other researchers such as Braun and Clarke (2006) highlight that writing-up is part of the analytic process. Indeed, many themes were adapted and developed throughout the current writing process. Accordingly, the present Analysis section is substantially different to the initial table of themes and thus its inclusion was felt to be redundant.

## **2.6 Sample**

Smith et al. (2009) suggest that samples should give data which answers your research question and be homogenous, so findings can be considered with other findings from similar samples. Accordingly, individuals were purposely selected who were living with ME/CFS and who had experienced an MBI. To classify individuals as 'living with ME/CFS', participants were expected to meet the criteria put forward by Fukuda et al. (1994). Although numerous criteria exist to classify ME/CFS, the Fukuda et al. (1994) criteria was selected because it is widely used in peer-reviewed research (see Eglinton & Chung, 2013; Morris & Maes, 2013; Poppe et al., 2013; Hambrook et al., 2011; Rimes & Wingrove, 2011; Martin & Alexeeva, 2010; Vanheule, Vandenberghe, Verhaeghe & Desmet, 2010 and Dickson et al., 2008). Moreover, it does not require input from a medical doctor and was found to be accessible. The original work has been developed into an easy to use checklist by the International Association for CFS/ME.<sup>6</sup> Since diagnosis is known to be an occasionally difficult and controversial process, an official diagnosis was not required for inclusion into the study for the purposes of equal rights.

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<sup>6</sup> The section on severity was excluded as it was felt irrelevant to the study's inclusion criteria.

My own criteria were created to classify whether individuals had experienced an MBI. Although the term is used in the literature (e.g. Grabovac et al., 2011; Vago & Silbersweig, 2012), and many intervention models incorporate a mindfulness foundation (see chapter one), there appears no overarching definition. MBI was defined as an experience which involves formal mindfulness practice, as well as communication with an individual whose role is to introduce mindfulness theory and practice. The term 'formal practice' was operationalised as 'sitting/lying and paying attention to the present moment without judgement'. This definition was developed in light of personal experiences and extensive reading. Furthermore, individuals who had experienced an MBI for less than six weeks were excluded so findings could be meaningfully compared to other research. Six weeks appears the minimum amount of time participants attend group-based MBIs for and is the minimum time one is likely to spend in therapy excluding premature drop-out. Six weeks was also felt sufficient to enable rich and detailed accounts.

There is room within homogenous samples to narrow or broaden the range of individual characteristics depending on the requirements of the research (Smith et al., 2009). Since, to my knowledge, this research is the first qualitative study exploring ME/CFS and MBIs, I wanted to illuminate the experiences of a range of individuals rather than a very select group. Relatively open recruitment criteria were therefore used – seeking people who had experienced a range of MBIs in a variety of contexts (see Appendix C). During recruitment, no individuals made contact who had experienced an MBI in any setting other than a course/group, or who had engaged in an intervention based on any model other than general mindfulness, MBSR, or MBCT. Therefore, for practical reasons, no participants had experienced an MBI through another medium such as counselling or psychotherapy, or one based on ACT, CFT, or DBT. Perhaps individuals with more varying experiences would have made contact should recruitment have targeted wider sources but, in

hindsight this was felt to be a positive development. A mix of group and one-to-one sessions and diverse modalities could have given a data set too varying for deep and meaningful analysis. Thankfully, all participants appeared to describe similar phenomena and I found their data meaningful to draw together.

Most individuals who volunteered were female. In keeping with interviewing a range, the three males who responded and met criteria were purposively selected. The remaining participants were chosen on a first-come-first-served basis which was consistent with interviewing a range as they differed from each other in age, time they had experienced ME/CFS, time they had been formally diagnosed and whether they described their ME/CFS as mild/moderate/severe. Eight interviews were conducted consistent with the four to 10 range Smith et al. (2009) suggest is appropriate for a professional doctorate. It was anticipated that eight participants would allow enough time for detailed analysis as well as provide sufficient data to capture a range of experiences.

Individuals were screened for thoughts of suicide or self harm with the intention of excluding those expressing any current or recent beliefs that life is not worth living or that they would be better off hurting themselves in some way. No individuals reported such thoughts recently, although seven expressed that they had experienced them some time ago (from 5-30 years past, with an average of 16 years). When such thoughts occurred, whether they were acted upon, when and how they went away, and current coping strategies were explored and the information used to make a professional judgement about whether risk was likely to be heightened by engaging in the study. I was confident no individual would be at increased risk and therefore excluded no-one.

## ***2.7 Recruitment***

Recruitment was conducted via two methods. First, the study was advertised during a talk given to a support group run by and for people with ME/CFS where the research proposal was outlined. Flyers were distributed afterwards (see Appendix C). Second, a mindfulness organisation was contacted and through them the aforementioned flyer emailed to individuals who had attended or facilitate(d) mindfulness groups through them. The latter method was particularly fruitful.

## ***2.8 Demographic questionnaire***

Gathering demographic information was initially decided against to guard from eliciting or exacerbating symptoms through activity. Also, presenting individual profiles would have compromised confidentiality as volunteers approached me after the recruitment talk in full view of the group. On further reading it became clear that some description of participants needed to be gathered and presented so findings could be compared against other research. Creating individual profiles but changing information to protect identity was considered. However, changing information sufficiently to ensure confidentiality would have created profiles so divorced from the original demographics they would be redundant. A profile of the group rather than each individual was decided upon. This can be seen in the next chapter (Analysis).

IPA can be used to conduct studies where comparisons are made between groups of interviewees. Here, participants are selected according to very specific demographics (Smith et al., 2009). In this context, it seems individual profiles would be required to create a meaningful analysis. The current research is not a comparison study and thus a group profile, rather than individual profiles, was believed sufficient.

Which information to gather was decided upon based on the intention to consider findings alongside existing literature. I considered how my participants could differ, then thought about which differences are frequently considered in research, as well as which might be useful to investigate in future. The following list was created: age, sex, ethnicity, time individuals have experienced symptoms of ME/CFS, whether individuals have been given a formal diagnosis and when this was given, present severity of ME/CFS symptoms, general severity of ME/CFS symptoms, type of MBI attended and when this was attended. How individuals learned about the study was also enquired after so the effectiveness of each recruitment method could be evaluated. This questionnaire can be seen in Appendix D.

## ***2.9 From initial contact to interview***

Individuals contacted me via email and telephone to express their interest in participating. An information sheet outlining the aims, procedure, and possible risks of the study was emailed back (see Appendix E). Importantly, this sheet contained information about the time and activities involved to ensure individuals were able to make an informed decision about whether participating was likely to elicit or exacerbate their symptoms. For those still keen to take part, a telephone call was arranged where individuals could be screened to ensure they were eligible. Volunteers were reminded of how long the call was likely to take and that information would remain confidential to myself and my supervisor excepting risk to self or others, or learning about a crime. All individuals but one reported experiencing persistent or relapsing fatigue lasting for six or more consecutive months and met at least four of the eight other symptoms Fukuda et al. (1994) expect a person with ME/CFS to experience. Three individuals reported co-existing conditions which, according to the Fukuda et al. (1994) criteria, excluded them from a label of ME/CFS. Each case was discussed with the research supervisor before a decision to decline them was made.

Particular care was taken when informing individuals they had not met the criteria. My personal belief is that peoples' experiences should be respected; if someone believes they have a condition, I consider this as a valid and meaningful truth. It felt important to validate individuals' experiences, particularly by not questioning the 'truth' of whether they 'have' ME/CFS or not. I opened the dialogue with them by explaining that I needed to present research as robustly as possible for it to be taken seriously. I highlighted that critics could question the credibility of the research if participants did not meet classification for ME/CFS. I suggested that the classification system I was using was somewhat crude and explained that as I was not medically trained it was the best available to me. It was emphasised that excluding individuals did not entail me saying I believed they did not have ME/CFS, but rather was me ensuring the research was as robust as possible.

I became concerned about the level of energy required to travel to a public interview venue after participants reported that travelling and being interviewed would likely tire them out and exacerbate symptoms. Although participants expressed being comfortable with this, researchers have an ethical duty to ensure research causes the least harm possible (BPS, 2010). Approval was therefore sought from my Universities Ethics Board to interview participants in their own homes (see Appendix F). Six participants chose this option.

The final chosen participants were emailed fortnightly with progress updates and likely interview dates. It was practical to inform individuals when they would be likely called for interview. It also felt inappropriate to allow a significant period of time to elapse before asking individuals to share what could be very intimate experiences. It was hoped that regular contact would also decrease the likelihood of dropout pre-interview. In hindsight, perhaps fortnightly contact was excessive. Indeed, one pilot participant said she did not require fortnightly emails and was left in a dilemma of

whether to respond. If I were to conduct the study again I would email approximately every four to six weeks.

After deciding to include a demographic questionnaire, participants were emailed to inform them of the change and to explain the reasoning behind the questionnaire's inclusion. At this point it was reiterated that the study was voluntary. This felt important as completing a questionnaire was not what participants had initially agreed to. After receiving confirmation that participants were happy to complete the questionnaire, this and a consent form (see Appendix G) was emailed for individuals to read/fill out in advance. The rationale for sending paperwork in advance was to enable individuals to spread out the research activity, reducing the likelihood of the process having a detrimental effect on symptoms.

The next step was to arrange a date, time and venue for interview - the public venue option being a room in a local hospital. A fully charged mobile phone was in my possession at all times and an appointed person called before and after each interview to ensure safety. This person was given the participant's name and address for the period of time the interview was being conducted, contact details for myself and the police, as well as written safeguarding instructions (see Appendix H). Before leaving I prepared according to the checklist in Appendix I. After returning, I debriefed using the framework detailed in Appendix J. This framework was developed from Smith et al. (2009), who ask researchers to consider each point contained within it when conducting IPA research.

## ***2.10 General ethical considerations***

The proposal for the current research was granted full ethical approval by the Department of Psychology at City University. The Ethics Release Form and Insurance Form pertaining to this can be viewed in Appendices K and L respectively. All materials containing identifying information are stored securely at

my house and electronically stored data is password protected. A small verbal debrief was conducted immediately post-interview and participants were provided with a debriefing form (see Appendix M). This form contained contact details for myself and my supervisor, as well as information about organisations who provide support to individuals with ME/CFS and those experiencing difficulties with their mood. Various forms of contact details (e.g. email addresses, telephone numbers and web-pages) for these organisations were supplied to ensure that help was accessible to all participants. As mentioned earlier, each participant was screened for suicidal thoughts or intention to self-harm. Particular care was taken throughout the study to prevent adverse effects on participants' symptoms, including the use of breaks throughout interview, spreading activity as much as possible and reducing travel. Individuals were frequently informed that participation was voluntary and that they could withdraw their data up to 24 hours post-interview without penalty. As elaborated upon in the section 'From Initial Contact to Interview', precautions were taken to ensure that participants' consent was informed.

### ***2.11 Question schedule***

Literature suggests that interview schedules enable interviewers to gather better quality data (e.g. Robson, 2011; Smith et al., 2009; Willig, 2008). Smith et al. (2009) suggest a five step procedure to creating a schedule. First, they encourage researchers to identify the broad area they wish to gather data about. Second, they advocate pinpointing the topics they want the interview to cover. Third, they recommend placing topics in an appropriate sequence. Appropriateness is decided via logic (e.g. chronological order), sensitivity (e.g. starting with less sensitive issues) and making a good start (setting the scene for further questions). Advice from Willig (2008) was also considered, who argues that researchers need to understand what the interview means to the participant in order to conceptualise

their contribution fully. Moreover, Robson (2011) advocates a 'cool off' period towards the end of interviews, aiming to diffuse any tension that might have built.

The broad area identified was 'mindfulness-based interventions' and the topic areas were participants' experiences of the concept of MBIs, participants' experiences of the practice of MBIs, and their experiences of life with ME/CFS during/after MBIs. Topics were kept in this order. A 'meaning of the interview' topic was added at the beginning and a 'cool off' topic inserted in the end. It seemed appropriate to start with the more general topic of the concept of MBIs, before moving onto exploring the practice of them which was anticipated to elicit specific memories and examples. It felt suitable to explore life with ME/CFS during/after MBIs a way into the interview, as this was thought to be the most sensitive topic.

The fourth step Smith et al. (2009) propose is creating appropriate questions to investigate each topic. They say six to 10 questions generate approximately 45-90 minutes of conversation in articulate adult participants. Below are the seven questions and prompts created for the current study.

1. Can you tell me why you volunteered to be interviewed?

*Possible prompts: What does the interview mean to you? Why did you reply to my flyer/email?*

2. Can you tell me, in your own words, what you understand a mindfulness-based intervention to be?

*Possible prompts: What is the aim? What happens? Why would somebody attend one? If you were writing an article explaining what mindfulness-based interventions are all about, what kind of things would you say?*

3. Can you tell me what it was like to attend the mindfulness-based intervention?

*Possible prompts: How did you experience the mindfulness-based intervention? How did you feel? What did you think?*

4. There may not be, but were there elements you found particularly positive, or particularly less positive about the mindfulness-based intervention? Can you tell me about this?

*Possible prompts: Did you experience any elements as especially helpful, especially desirable, especially less useful, or especially difficult? Perhaps the experience was fairly middling?*

5. Did the mindfulness-based intervention influence what it is like to live with ME/CFS or did it have no influence? Can you tell me about this?

*Possible prompts: Did the mindfulness-based intervention have an effect on life with ME/CFS or did it have no effect? How do you think life would be if you had not gone to the mindfulness-based intervention?*

6. Is there anything you would like to elaborate on, or anything you would like to share that we have not talked about?

*Possible prompts: Is there anything you would like to say more about, or anything that we have not covered that you would like to?*

7. We're coming towards the end of the interview now. How have you found it?

General prompt: Can you tell me a bit more about that?

General probe: What do you mean by X?

The following table details which questions relate to each topic area.

*Table 1: Topic Areas and Related Questions*

| Topic Area                                                         | Related Questions        |
|--------------------------------------------------------------------|--------------------------|
| Meaning of the interview                                           | Question one             |
| Participant's experiences of the concept of the MBI                | Question two             |
| Participant's experiences of the practice of the MBI               | Questions three and four |
| Participant's experiences of life with ME/CFS during/after the MBI | Question five            |
| Cool off                                                           | Questions six and seven  |

Willig (2008) and Smith et al. (2009) say the success of semi-structured interviews depends on the rapport established between interviewer and interviewee. As well as easing participants into the interview with less sensitive topics, questions were designed to be polite and prompts were prepared should participants be unsure how to answer questions. Prompts were hoped to reduce anxiety in this event. It was hoped that by taking these steps the research would be being conducted ethically, consistent with the BPS research guidelines (2010). The cool-off questions were also included in the interest of ethics. It was hoped that question six would signal that the interview was drawing to a close, something which was felt particularly important for participants with ME/CFS as they may be more anxious about time boundaries in the knowledge that symptoms are exacerbated by activity. It was hoped that question seven would act as a grounding technique, anchoring the client in the here and now and switching attention from any distressing

experiences so they could continue with the rest of their day without too much difficulty.<sup>7</sup>

Consistent with the research's aim to illuminate the life-world, questions were designed to elicit responses grounded in individual experience rather than superficial or hypothetical answers. For example, it was felt that question two might communicate I was looking for an answer already 'out there' and thus the phrase "in your own words" was included to challenge this. A 'workshop' rather than 'warehouse' question was used in the prompt "if you were writing an article explaining what mindfulness-based interventions were all about, what kind of things would you say?" 'Workshop' and 'warehouse' questions were derived from Dr Don Rawson's lectures at City University London. Rawson argued that some questions are likely to elicit pre-packaged 'warehouse' answers, and others create new 'workshop' answers. It was hoped, in accordance with Rawson, the 'workshop' prompt would elicit richer and more personal data.

Aligning with Smith et al. (2009), questions were designed with the aim of making as few assumptions as possible about what concerned participants or what their experiences might have been. Questions and prompts were therefore designed to lead participants as little as possible and allow for multiple responses. For example, the prompt "can you tell me a bit more about that" asks for more information whilst giving little indication as to what that information might be.

The fifth step in the procedure suggested by Smith et al. (2009) involves the researcher discussing their question schedule with another person – a potential participant, co-researcher, or supervisor – and editing it accordingly. Drafts of the above schedule were shared with two colleagues also conducting their thesis

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<sup>7</sup> Grounding techniques are often used in trauma work to ensure clients are not re-traumatised by the recounting of their experiences. Examples of how grounding is used in trauma work are given in Cohen, Mannarino and Murray (2011).

research and my research supervisor. Their input was particularly helpful and changes were made to the schedule based on their feedback.

### ***2.12 Pilot interviews***

Three pilot studies were conducted consistent with recommendations given by Robson (2011), Smith et al. (2009) and Langdridge (2007). Robson (2011) says two types of pilot study exist - the 'pre-test' (where researchers trial different approaches) and the 'dress rehearsal' (where data collection plans are followed as per the real study). The current pilot studies contained both 'pre-test' and 'dress rehearsal' elements and were conducted for numerous reasons. It was hoped that by conducting pilot studies I would learn the question schedule in advance as referring to it mid-interview can be distracting for the interviewer and interviewee (Smith et al., 2009). It was also hoped the pilots would raise any practical problems in advance as interviews can be uncomfortable and unfit for purpose if interviewers are unprepared (Langdridge, 2007). It was further anticipated that feedback would be gathered which could be used to refine the study process.

The first study was conducted with a friend (M) who took on the role of a person with ME/CFS who had experienced an MBI. Although M does not have ME/CFS, she has good knowledge of the condition and of mindfulness. We arranged to meet at the hospital venue and ran through the interview process as I would with real participants. The second and third studies were conducted with my first and second participants. They were interviewed and then asked for feedback about the process. During participants' screening conversations the extra activity involved in being a pilot participant was detailed and participants were given a choice not to do this. Participants were not informed if they had been selected to give pilot feedback before engaging in the interview process as it was felt knowing might affect the quality of the data gathered. Apart from suggesting that researchers ask for feedback about their question schedules, the literature consulted gave little

guidance as to what feedback to request. Based on what I personally felt was required, I asked about what the experience of the interview had been like, how participants had found the interview questions and whether participants wished to share any other information about the interview process (see Appendix N). It was decided to use data gathered from pilot participants' initial interviews in the final analysis, excluding that collected from M. The data was rich, meaningful, answered the research question and it felt wasteful not to use it. It also felt unethical to ask individuals to invest in the research process and not utilise their data.

### ***2.13 Recording equipment***

Langdridge (2007) says using correct equipment to record interviews is imperative. Consistent with Langdridge (2007) and Dr Rawson, it was decided to record interviews on two Dictaphones so data would not be lost should one fail. It was ensured that batteries were fully charged and spares were taken to interviews as backup.

### ***2.14 Conducting the interviews***

Consistent with advice from Smith et al. (2009), time was spent before interviews explaining what the process might be like. Participants were informed that I was interested in their experiences and it was stressed that there were no right or wrong answers. It was suggested that interviews might take the form of one-sided conversation - I speak little but prompt individuals should they be unsure what to say. It was also explained that some questions may seem self-evident. Examples of self-evident questions were given and the rationale behind them described - wanting to avoid assuming knowledge and instead learn about what phenomena meant to participants. Interviewees were encouraged to take their time thinking and talking. It was explained that individuals were welcome to talk about whatever they

liked, but, consistent with feedback from my pilot studies, it was communicated that I would intervene should participants be too divergent from the topic.

During the interviews I aimed to follow the guidelines stipulated by Smith et al. (2009). I tried to speak slowly and clearly, anticipating this would encourage participants to do similar. I aimed to enter participants' worlds, creating questions based on what they communicated. I tried to bracket as many assumptions as possible, making a conscious effort to ask about concepts which at face value I believed I understood. Both verbal and non-verbal encouragers were used, e.g. 'mm' and nodding, to encourage rapport, and participants were allowed to talk without interruption, being prompted when speech came to a natural end. Key words or observations were noted during conversation and were returned to in such breaks. Questions were asked one at a time to avoid confusing participants and to help make analysis easier. I tried to monitor participants throughout interviews, providing reassurance and encouragement when needed. The question schedule was used as a guide rather than a rigid structure.

### ***2.15 Debriefing the interviews***

After returning home, I asked myself a series of questions designed to aid reflection on the interview, responding as one might if writing a journal. The aim was to bring awareness to my fore-structures so I could bracket these assumptions as much as possible in consecutive interviews. The debriefing questions were founded on Smith et al. (2009) who suggest researchers may notice particular experiences during the research process. These questions can be observed in Appendix J.

### ***2.16 Validity, quality and ethics***

Many researchers suggest that it is important to consider validity, quality and ethics when conducting qualitative research (Willig, 2013; 2012; 2008; Smith et al., 2009). Smith et al. (2009) explains that traditionally, qualitative research has been

evaluated against quantitative criteria. However, many argue that qualitative research should be assessed against its own criteria more appropriate to the qualitative paradigm (Smith et al., 2009). Smith et al. (2009) converse favourably about two established guidelines, those proposed by Elliott, Fischer and Rennie (1999) and Yardley (2000).

The current study is evaluated below first according to Yardley's (2000) criteria and second according to Willig's (2012) writings on the ethics of interpretation. Yardley's (2000) criteria was chosen as Smith et al. (2009) provide a clear description of how IPA can address this, and thus provide an accessible guideline to assessing IPA research. Willig's (2013; 2012) writings appear to go further in contemplating the ethical implications of interpretation and were therefore felt important to consider as well.

Yardley (2000, as cited in Smith et al., 2009) proposes four broad principles against which qualitative research can be evaluated – 'sensitivity to context', 'commitment and rigour', 'transparency and coherence' and 'impact and importance'. She argues that in high quality studies, researchers seek to establish a good understanding of the philosophy and history behind their approach. As illustrated earlier, I worked to generate a thorough understanding of the history and philosophy behind IPA, and how this shaped the development of the approach. Yardley (2000, as cited in Smith et al., 2009) also argues that high quality research shows sensitivity to the socio-cultural milieu in which the study exists. It is thought the current research displayed particular sensitivity to the wider social background of ME/CFS as its IPA approach was chosen specifically to communicate that participants' experiences were being taken seriously. Similarly, Smith et al. (2009) suggest that competent IPA researchers show sensitivity to the interview interaction. As described earlier, numerous steps were taken during interviews to put participants at ease and to guard against symptom exacerbation.

Yardley (2000, as cited in Smith et al., 2009) argues that it is important for researchers to be committed to their topic. She suggests that committed researchers engage with their topics in capacities other than research, and show commitment by developing skills in their analytic method. As noted earlier, the research topic is one I have significant personal experience of. Reflections on my personal experience will be explored in more depth later on. I also joined an IPA group during the course of the research to enhance my skills in this area.

Morse, Barret, Mayan, Olson and Spiers (2000, as cited in Allen, 2011) suggest that rigorous qualitative study involves monitoring methods and analysis. Similarly, Willig (2008) cites Henwood and Pidgeon (2002, as cited in Willig, 2008) who state that good qualitative researchers keep comprehensive documentation of what they did and why. A diary was kept during the current research process where observations or musings upon the process were recorded. Example extracts can be seen in Appendix O.

Smith et al. (2009) suggest that proficient IPA researchers demonstrate transparency in their write-ups. They hold that researchers demonstrate this by judiciously describing how they selected participants, developed interview schedules, conducted interviews and the stages engaged in during analysis. As the reader may have noticed, I have attempted to clearly detail the above steps, the thinking behind each decision and the literature consulted in the process. Smith et al. (2009) also state that good quality write-ups are coherent, with themes hanging together logically and ambiguities dealt with clearly. I have attempted to report a coherent study and to do so have engaged in extensive drafting and redrafting, seeking and incorporating feedback from colleagues, my IPA research group and my supervisor. Smith et al. (2009) also say that coherent IPA write-ups link well with their theoretical underpinnings. In light of this a conscious effort has been made to

report the research cautiously, avoiding sweeping statement or expressing interpretations as 'fact'.

Yardley (2000, as cited in Smith et al., 2009) argues that regardless of how well research is conducted, whether it is truly valid depends on whether it tells readers something important, interesting, or useful. It is my opinion that the current findings illuminate important experiences from which practical steps have emerged that inform best practice. It is hoped the research will prove its validity in being published and, to this end, an article based on the current research has been created for this doctoral portfolio.

Smith et al. (2009) explain that high quality IPA research shows sensitivity to the raw material gathered and to the analysis of this material. Similarly, Willig (2013; 2012) has written extensively about ethical issues which manifest during interpretation. She explains that interpretation is always a process of transformation. As the interpreter makes sense of the material they are engaging with it will always be altered in some manner to allow understanding to occur. As noted earlier, what the reader is eventually presented with is not thought to represent 'the truth'. Rather it is considered a version of reality, notably one version of many. As Willig (2012) articulates, "the interpreter selects one of many possible interpretations and foregrounds this by putting it into words" (p. 46). Willig (2013) explains that in being presented with one interpretation, readers are restricted in the options they have to react to the data. The interpreter is therefore automatically afforded much power. They have a significant amount of control over what comes to be known about another person's experience.

As Willig (2013) highlights, with such power comes responsibility. Our interpretations can hold consequences both for the participants whose behaviour has been interpreted and for wider society (Willig, 2013). It could be argued that as

psychologists we are particularly powerful, and thus must be especially careful in our statements. Indeed, Parker (1999) affirms that as psychologists we are often assumed expert and our messages frequently and easily internalised. It could be further suggested that as psychologists in the area of ME/CFS we are perhaps more powerful than we might usually be. This is because the ME/CFS population often appear lacking in power, their illness frequently delegitimised and the 'yuppie flu' discourse commonly adopted (e.g. Brooks et al., 2014; Dickson, Knussen, and Flowers, 2007; Edwards et al., 2007; Moss-Morris and Petrie, 2000). Thus, the ethical obligation of the psychologist researcher in the ME/CFS field becomes especially important.

Willig (2012) suggests that there are certain safeguards researchers can take to uphold ethical practice. The first of these is "keeping the research question in mind and being modest about what the research can reveal" (p. 56). Willig (2012) explains that the researcher always needs to ask questions of the data in order to generate findings. She highlights that consequently, it is essential for the researcher to be fully aware of their motives in approaching the data. This is because such motives will always shape the findings. Certain steps were taken to ensure that I was as aware as possible of my motives in approaching the data. A simple way of doing this involved the research question being written down and frequently referred to throughout all steps of analysis. I also asked myself what I meant exactly by 'how do people with ME/CFS experience MBIs'. In doing so I generated a greater awareness of the questions I was asking of the text. On a deeper level, time was spent exploring what my less conscious motives might be. In addition to these being reflected upon in my own time, the help of a colleague was enlisted who interviewed me about why I chose the topic and what I was hoping to achieve by it.

The second safeguard Willig (2012) talks about is "ensuring that the participant's voice is not lost" (p. 57). In light of this, Willig (2012) mentions Kvale (2003, as cited

in Willig, 2012) and Latour (2000, as cited in Willig, 2012) who state that it is important for individuals to be able to object to what is said about them. Often this is achieved via 'member checking' where interpretations are presented to participants and amended as appropriate. Unfortunately, due to time pressures, member checking was not viable for the current study. Willig (2012) explains that in the absence of the participant being consulted, researchers must acknowledge that there is a disparity between the participants' accounts and the claims the researcher makes about their meaning. This is thought to make for an ethical interpretation. It is hoped this discussion will go some way towards acknowledging such distance in the current study.

The third safeguard Willig (2012) acknowledges is "remaining open to alternative interpretations" (p. 59). She explains that it is important for researchers to reduce the risk of interpretations closing down rather than opening up meaning. Willig (2012) suggests that one way researchers can remain open is by avoiding, as much as possible, imposing pre-conceived narratives on the data. As noted above, 'closing down' meaning has been guarded against by incorporating a 'body-focus' into analysis and through keeping a reflexive diary. It was hoped the diary would increase my awareness of the analytic choices I was making and why they were being made.

According to Brinkmann and Kvale (2008, as cited in Willig, 2012), if one looks at a situation without considering temporal or social influences, data can more easily be misunderstood and misrepresented. Consequently, Willig (2012) explains that contextualising the data is another method of remaining open to alternative interpretations of it. Here researchers focus on both the time the data was collected and the wider context it can be situated within. As noted earlier, participants were asked why they volunteered to be interviewed as well as their experience of the interview after it had been conducted. It was hoped such steps would guard against

severe misunderstanding and misrepresentation of the data. A conscious effort was also made to pay attention to how participants' experiences fitted into the wider context of their narrative during analysis.

### ***2.17 Reflexivity***

Smith et al. (2009) affirm that reflection is central to IPA, particularly in aiding the bracketing process so in-depth analysis can be produced. Since I have a strong connection with both mindfulness and ME/CFS, it was anticipated that my existing beliefs may influence every part of the research process. Consequently, it was felt that reflection was important throughout the entire process, from generating the research question to writing up the study. It seems that the research diary is a well-established reflective method in qualitative research (e.g. Frost, 2011; Bloor & Wood, 2006). Consequently, a diary was kept throughout the full research process. The following section exemplifies and explores some of the issues debated within this diary. It is hoped that the reader will gain insight into some of the issues thought important for deliberation and my process in exploring them.

I was encouraged during lectures to reflect on why I decided to conduct this research. On contemplation, it was found that although I could argue a rationale embedded in literature, I had perhaps not fully considered why I chose this topic personally. It became apparent during reflection that my hopes for the project were similar to the hopes held for many years with my mother. I wanted to help people with ME/CFS the same way I wanted to help her. I wanted to discover a way of making life easier. Mindfulness, the new and highly esteemed intervention supported by a plethora of research, was my answer. Other research topics were not considered. Perhaps had I not so desperately wanted to help, I would have considered other fields and questions.

When one participant, Harriet, said “I thought you might be very pro-mindfulness or something” (21-24) my reply was that I was not affiliated either way. From a ‘research point of view’ I was unbiased, the study’s aim being to learn about peoples’ experiences, good, bad and in-between. Retrospectively though, it seemed obvious that part of me was and is pro-mindfulness. However hard I tried not to be, I must have always been hoping that mindfulness would be the thing, that one thing that makes a difference. Despite trying to remain unbiased it is inevitable that many of my responses during interviews will have been pro-mindfulness. Perhaps this was very subtle. Although I listened to participants when they spoke about less positive experiences, maybe the more positive experiences were followed with more gusto; a glimmer of enthusiasm absent from the less positive experiences shining through.

This desire to make a change will have also inevitably clouded my analytic lens, other available themes probably overshadowed by those fitting the ‘make a change’ mould. It is certainly evident that the findings and final write-up is influenced by this desire to help. The Analysis talks about participants’ experiences in terms of what they found beneficial and not beneficial, and the Discussion considers how we can apply these findings in a practical manner to inform best practice.

Analysis was also likely shaped by the placement I began whilst exploring the data for emergent themes. ACT was the sole approach covered at the placement. I connected strongly with the philosophies of this model and found my approach to life changing the more I read upon the subject. Subsequently, I found myself recognising ‘ACT concepts’ when analysing transcripts. I felt excited when this occurred. Perhaps, rather than mindfulness per se, it would be ACT that could make the difference that was so desired. A conscious effort was made to record this process and to bracket my ACT lens as much as possible. The research diary allowed for tracking of ACT terms (e.g. defusion) and thus the partial bracketing of

such. Keeping this diary meant I was reminded of terms and concepts to avoid during analysis, which helped me to view the data from different perspectives.

We can see that my ACT lens remained present as ACT is mentioned frequently in the Discussion section of this write-up. ACT is suggested as an avenue for future research and the qualities it might bring to intervention explored. The utility of this ACT focus was deliberated in the research diary. The main disadvantage to the lens was thought to be the restriction on considering findings from other viewpoints. Advantages were thought to be a detailed discussion from which much practical application might emerge and concrete avenues for future research suggested. In light of such consideration, I gave myself permission to 'run with' my ACT lens, ultimately feeling that this was a useful path to take. The decision seems compatible with the IPA stance since, as explained earlier, although bracketing is prioritised in the approach, it is believed that no knowledge can exist outside of interpretation (Smith et al., 2009).

Another topic debated in the diary was my concern that the research was developing inconsistently with participants' original agreements. Recruitment material stated that information would be accessed only by myself and my supervisor. However, it later became clear that help was needed from a 'safety person', assistance might be required in transcribing and that transcripts might need to be discussed with colleagues. The consent form was amended to say that information would be accessed only by myself and 'the research team'. On one hand, it felt unethical to ask participants to agree to something different than originally stated, seemingly inconsistent with informed consent. Conversely, the changes felt necessary to yield safe and credible research. Debating such issues in my diary increased my awareness of them and encouraged me to seek supervision.

### **3. Analysis**

Smith et al. (2009) suggest that the aim of the analysis section is “to present a clear and full narrative account of what you have learnt about the participant” and, obviously, to illuminate their experiences (p. 110). Smith et al. (2009) explain that it is usual not to refer to the extant literature at this stage. In accordance with this guidance, minimal theory is included in the following section as it was thought that weaving it in at this stage might detract from illuminating participants’ stories and thereby counteract the aim of the study. It is hoped that a coherent narrative which does justice to participants’ experiences is communicated. For this purpose, some repeated words were deleted from participants’ accounts. Words were also deleted and on occasion changed to maintain confidentiality. All participants chose their own pseudonyms. The symbols ‘[ ]’ indicate that material has been omitted, ‘[text]’ refers to explanatory material added by the researcher, and ‘...’ shows that the interviewer’s speech has been removed. Smith et al. (2009) suggest that it is useful to include a profile of participants to help readers embed accounts within a context and engage with individuals’ narratives. A profile of the group will therefore be given. In accordance with the guidance given by Smith et al. (2009), a brief overview of the findings will then be presented, followed by an in-depth exploration of the master and sub-themes. Finally, the overall narrative of participants’ experiences as understood by myself is summarised.

#### ***3.1 Profile of group***

I interviewed five females and three males. The average age of the group was 49.4 years, (a range from 36 to 66 years). Seven participants identified as ‘white-British’ and one ‘Asian-white’. Individuals described experiencing ME/CFS symptoms for an approximate average of 14 years 5 months, (a range from 3 to 25.5 years). All but one had received a formal diagnosis. Participants reported holding diagnoses for an approximate average of 11 years 9 months, (a range from 2 years to 25 years, 5

months). One participant described his ME/CFS as generally severe, four as 'moderate', one 'mild-moderate', and two 'mild'. All had engaged in at least one course incorporating mindfulness, attending a minimum of seven or eight sessions. Four had either practised mindfulness or meditation or read up on the subject before attending a formal intervention. Four had engaged with further courses, classes, or sessions following their initial intervention.

### ***3.2 Brief overview of findings***

The data communicated a mixed view of mindfulness. While some participants reported mostly positive accounts, others gave less positive reports and some participants captured both positive and negative experiences in the same interview. Moreover, participants' reports indicated that it was not always mindfulness per se that was helpful. Rather, for some, it appeared that it was the more generic aspects of the group experience that were most useful. The findings are presented in four main themes. These, and their counterpart sub-themes, are as follows:

#### **1. The gift of mindfulness**

- Acceptance

- Self-soothing and control

#### **2. Struggling with doubts and understanding**

- Scepticism, cynicism, and doubt

- Facilitator-related barriers

#### **3. The vulnerable self**

- The imperative of symptom management

- Expecting the worst

#### **4. Healing relationships**

- Validation and belonging

- Hope and engagement

### **3.3 Master theme one – *The gift of mindfulness - “If I hadn’t discovered it, I think I would be in a very different place”***

Individuals often spoke about what mindfulness ‘gave’ to them or what it allowed them to do. It is for this reason I entitled this theme ‘The gift of mindfulness’. The theme therefore considers what ‘gifts’ individuals talked about mindfulness affording to them. In particular, we look at how individuals said they found mindfulness helpful. Here we explore individuals’ experiences of managing their symptoms and the limitations those symptoms had placed upon them. In *Acceptance* we see how the philosophy and practice of acceptance influenced individuals both physically and psychologically. Similarly, in *Self-soothing and control* we see how these concepts (self-soothing and control) influenced individuals, again both physically and psychologically.

#### **3.3.1 Acceptance**

Acceptance appeared to be an important factor in how individuals coped with their symptoms and the impacts of these symptoms upon their lives. At least six participants appeared to associate acceptance with mindfulness. Mindfulness philosophy was believed to teach acceptance and mindfulness practice thought to embody it. Lucy said:

“The two biggest improvements of mindfulness for me [] [are] letting me focus on what mental state I’m in, and kind of acknowledging that a chronic illness does have its mental impact [] it is stressful”. (Lucy: 2176-2187)

Lucy spoke about mindfulness as if it gifted her acceptance. It seemed that before learning about mindfulness, being emotionally affected by her condition felt somewhat unacceptable and less than positive feelings were pushed aside. Lucy described mindfulness as giving her permission to openly consider what her mental

state could be, rather than dismissing it as anything other than okay. I get the sense that before mindfulness Lucy was acting in defence, protecting herself from whatever it meant to her to be mentally impacted.

We can see that Lucy spoke about mindfulness gifting her acceptance in terms of her emotions, mindfulness allowing her to acknowledge the impact her condition had upon her. Richard recounted a similar experience. Although he reported finding it difficult to accept the specific restrictions his ME/CFS placed on him (e.g. being limited in his ability to play with his granddaughter), Richard described mindfulness as helping him to accept at a more general level that he had a condition which affected his life. He said:

“It’s [mindfulness is] basically giving yourself permission to accept the consequences of the condition”. (Richard: 2058-2062)

Richard also talked about putting the acceptance philosophy into practice in his general life. He gave the example of a traffic jam:

“I try to stop myself getting agitated or getting stressed by the traffic, and say ‘the traffic is what it is, the lights are what they are. [] There’s no point in worrying about those things that you can’t control, just accept them, and you will get there when you get there’.” (Richard: 186-197)

Here we see that Richard was attempting to prevent a stressed or agitated mood state by adopting an acceptance philosophy. Daniel spoke about a similar process, choosing a path of acceptance rather than engaging with other thoughts likely to lead to emotional distress. In contrast to Richard, it seemed that Daniel was able to apply the acceptance philosophy to specific ME/CFS-related limitations:

“There’s kind of more [] acceptance. [] You accept this. Well, what am I doing now, erm, never mind what I could be doing. This is what I’m doing, and if it means I’m sat here in the lounge drinking a cup of tea and nothing more, [] then okay, that’s what I’m doing now. I’m just going to focus on that, rather than thinking about what might have been or what could have been.” (Daniel: 1619-1640)

We can see in the above account that Daniel presents two different ways of reacting to his situation. The first would be to follow the path of thinking about “what [he] could be doing” and “what could have been”. In this option, “[sitting] in the lounge drinking a cup of tea and nothing more” would not have been “okay”. Daniel spoke about mindfulness as giving him a second option, the choice to put out of his mind what he might be doing if he was more physically-able, focussing instead on the present moment. As a result of mindfulness, Daniel appeared to have made the decision that sitting in the lounge drinking tea was okay for the time being. It was as if, post-mindfulness, Daniel was able to re-appraise his situation through the eyes of acceptance and found the situation sufficient for him for the time being.

Similar to Richard and Daniel, Caroline spoke about adopting an accepting approach to the limitations her illness placed upon her, as a result of learning about and practising mindfulness. She talked about accepting bodily sensations too, in particular the sensation of pain. Below is her account of what she understood mindfulness to be about. This account gives insight into her personal processes as regards mindfulness and acceptance:

“It’s about trying to get into the moment; trying to acknowledge your thoughts but then letting go, just accepting them. [] It’s about trying to sort of feel how

your body is right now, and just letting your body be  
how it is right now. [] Whatever's going on in your  
head, acknowledge it's going on but then letting go".  
(Caroline: 535-546)

Caroline gave insight into what this "letting go" process did for her. She said:

"The pain isn't as bad. The illness with ME isn't as  
stressful as it can be." (Caroline: 574-576)

Like Caroline, Nadia spoke more about the specifics of mindfulness and acceptance, rather than a general philosophy. Nadia talked about mindfulness practice embodying a compassionate and accepting attitude to the limitations she encountered as a result of her ME/CFS. She described practice as:

"A very nice warm way of kind of accepting some of  
those limitations". (Nadia: 881-884)

It became clear in Nadia's interview that accepting her limitations was also an act of accepting herself. This was something she reported struggling with since being diagnosed with the condition. Patricia also described a history of struggling with self-acceptance, partly as a result of her illness. Similar to Nadia, Patricia spoke about mindfulness leading to an acceptance of herself as she is, limitations and all:

"My mind at some level is still reeling from  
permission to, that whatever I am is good enough".  
(Patricia: 1683-1688)

Like Lucy and Richard, Patricia described mindfulness as giving her "permission" to accept herself. It seemed that for many participants, mindfulness allowed them to change how they related to themselves, leading to treating themselves with openness and non-judgement.

Nadia's phrase "a very nice warm way" (881-882) connotes for me a process of self-soothing. This process appeared present for other participants also and seemed to be another 'gift' that mindfulness afforded. This is considered in more detail in the following section.

### **3.3.2 Self-soothing and control**

Seven participants gave accounts which appeared to describe a process of self-soothing. Interestingly, it seemed that experiences of self-soothing were often bound up with experiences of control. Feeling in-control of one's illness or situation appeared to go hand in hand with being able to soothe one's emotions. Patricia spoke about mindfulness as helping soothe her difficult emotions and urges. Here the concept of transience appeared pivotal:

"However passionate I feel and however angry I am  
about whatever, however desperately I want to do  
whatever, it will pass." (Patricia: 2011-2015)

Patricia said she had learned from practising mindfulness that all sensations and emotions are transient. This knowledge of transience seemed to make difficult emotions manageable for her. Patricia talked about transience as if it had no bounds, that whatever the intensity of the emotion it could be soothed by the knowledge that "it will pass". It is as if Patricia experienced an overall sense of acceptance, which allowed her to self-soothe and tolerate her dissatisfactions.

Like Patricia, Nadia talked about the transience philosophy of mindfulness as mediating her mood. This was in the context of her mood being negatively impacted by her symptoms. Again, transience appeared to be a mechanism of self-soothing. Knowing that experience is more momentary than constant appeared to afford Nadia a sense of hope:

“Even though you’re in pain or extreme pain, at some point it won’t always be like that [] knowing that that’s your experience at this moment rather than, you know [] your constant experience [] that offers that little chink of light that you need sometimes, to help you feel a bit more positive, to feel a bit better about yourself.” (Nadia: 289-309)

It seemed that knowledge of transience resulted in Nadia feeling more positive, particularly about herself. Describing being offered a “chink of light” suggests that experiencing the condition, in this case pain, could sometimes be a very dark and overwhelming experience for her. There is a sense that without this “chink” Nadia would be left feeling negative, perhaps critical towards herself.

As did Nadia, Patricia and Lucy, Richard talked of using mindfulness to self-soothe too. Rather than focussing on transience, Richard spoke about employing the body scan as a method of coping with his symptoms and mood on waking:

“When I wake up [] I’m sweating very often, particularly my legs, but when it’s bad nearly all of my body. My legs are tingling and my chest is hurting sometimes, and I’m feeling nauseous [] it can be a very negative experience [] I do it [the body scan] just really just to try and calm myself down, and to stop myself [] getting into a kind of depressed state.” (Richard: 1593-1632)

Richard described using the body scan as both a relaxation technique and an anti-depressant. He talked about the practice as a preventative measure, as averting a “depressed state”. I get the sense that low mood came easily to Richard and that

the body scan was used to gain some control over this. Like Richard, Irv described self-soothing and gaining control through practice:

“I can just feel myself sink into the bed and start to breathe properly, and I get this release, I don’t know if it’s endorphins but it certainly feels like that ... [] it feels a little bit euphoric [] and I feel that I’ve got a little bit more control back.” (Irv: 344-363)

Just after the above extract, Irv described the control he gained as being in direct opposition to “tormenting [himself] with [his] thoughts” (364-365). I believe that Irv found his sense of control taken away by his condition, which procured agency of both his body and mind. There is a sense that breathing in a particular way took the control back.

Caroline’s account was similar to Irv’s. She spoke about using a breathing technique to ‘switch off’ from her thoughts and calming down as a result. Like Irv, the breathing technique appeared to be a mechanism of self-soothing:

“The breathing, that helps to sort of calm you down and [] it puts your focus on your breathing, to try and switch you off from everything else that’s going on in your head.” (Caroline: 586-591)

Daniel’s account seemed to embody both the transience concept that Nadia and Patricia talked about, as well as the thought-managing focus that Caroline and Irv spoke of. Daniel’s account shows him using the transience philosophy as an alternative to focussing on what could have been unhelpful and distressing thoughts. It seemed that Daniel was using this philosophy in an attempt to self-soothe and improve his mood:

“It’s very easy to just say ‘it’s a bad day, here we go again. It’s another awful day’. But you don’t have to become obsessed with that. It’s just a bad day. The next day you might feel better. [] Okay, that’s all it is.” (Daniel: 331-340)

Daniel’s account seems to embody both choice and alternative coping mechanisms. It appeared that mindfulness gifted both of these to him. Daniel gave a clear account of how he might have behaved pre-mindfulness, becoming “obsessed” with feeling ill and engaging in a catastrophizing process. It seemed that mindfulness allowed Daniel to soothe himself by taking a more balanced view of the situation, ensuring he did not make his difficulties more than they needed to be. The phrase, “okay, that’s all it is”, seems to me like self-compassionate self-talk and again appears to embody a self-soothing process.

Lucy also spoke about mindfulness, transience and thought-management. Like Nadia, Lucy talked of transience helping her to cope with her pain. She said:

“It helps you not to think just ‘oh I’m in pain’ [] and that’s the kind of limit of your thoughts. It helps you to [] realise that, you know, everything’s transient; that the pain’s not there forever and it changes. [] If you can tap into that, then that takes your mind off this ‘pain pain pain’”. (Lucy: 1853-1866)

Again Lucy described gaining control by being able to self-soothe via the concept of transience. She reported that tapping into the knowledge of “everything’s transient / it changes” had been helpful to her in terms of moving her attention from thought patterns she described shortly after as a “barrier” (line 1867).

As we have seen, participants seemed to gain many benefits from practising mindfulness and learning about its philosophies. Not all accounts were positive

however. As mentioned earlier, some participants also presented a mixed opinion whereby they appeared to have experienced both good and bad elements of mindfulness. The following section recounts the latter, focussing not only on less positive experiences of mindfulness, but less positive experiences of the interventions as a whole.

### ***3.4 Master theme two – Struggling with doubts and understanding – “I was quite a cynic initially”***

No participants described their journey towards mindfulness as a smooth one. Individuals' accounts were full of struggles and reported misunderstandings. These struggles were interpersonal, intrapersonal and between oneself and mindfulness theory and practice. Hence, this master theme is entitled 'Struggling with doubts and understanding'. We start in *Scepticism, cynicism, and doubt* by considering when participants described a lack of belief in the interventions and what this was like for them. Then, in *Facilitator-related barriers*, we reflect on barriers to engagement focused solely around therapists.

#### **3.4.1 Scepticism, cynicism, and doubt**

At least seven participants described encountering the course and the material with some reservations. Three expressed being doubtful before the course began that the techniques would be useful. For example, Irv said:

“When someone says ‘but if you learn to breathe correctly or in a more appropriate fashion [or] beneficial way you will see a difference’ [] I’d read about it but I didn’t really think it would make any difference.” (Irv: 1073-1081)

This is somewhat similar to Lucy who, as described elsewhere, almost did not attend the intervention because she anticipated it would not help her. Daniel also

spoke of doubts potentially affecting attendance. He referred to religion and anticipating that facilitators might attempt to impose this on their attendees:

“Some people might think, ‘oh my gosh you go to somewhere like that and they’re going to try and er convert you to Buddhism’ [] ... [] I wondered at first whether it would be like that.” (Daniel: 779-811)

It seemed that eventually, none of these reservations impacted upon individuals’ engagement with the course or material long-term. Each participant described themselves gaining from what they were taught. Whereas Lucy and Daniel’s reservations appeared to diminish during the course, Irv remained sceptical of the material throughout, experiencing a change of heart some months after. For Irv, it was the perceived simplicity of the techniques which acted as a barrier, leading him to conclude that they were not “useful”:

“They didn’t really register as being useful. In fact, quite often I felt resentful because I was being told things that sounded so fundamental. [] I thought, ‘well, I want to hear something a little bit more technical’.” (Irv: 290-298)

Interestingly, after time, the simplicity of the techniques changed from a barrier to an enabler:

“I then, some months later, realised that it’s simplicity that is the key. It’s not too difficult to learn to breathe properly, it’s not too difficult to have a pattern of relaxation, and it benefits you immensely.” (Irv: 298-306)

It seems that it was the application of the techniques and the actual experiencing of benefits that led to Irv’s reappraisal. Unfortunately, Harriet had quite a different experience. Her hopes for the course remained unmet as she lacked connection

with the material and noted little improvement. Harriet described remaining cynical throughout the course, continuing to be doubtful of the utility of mindfulness for her at the interview. Harriet seemed to have missed the essence of mindfulness, understanding this and relaxation as the same thing:

“It’s relaxation [] it’s nothing new”. (Harriet: 1130-1138)

Since Harriet had practised relaxation for many years, this misconception appeared to be a significant block for her, leading her to conclude that there was nothing more she could get out of the practices than she already had. Not only did this appear hugely disappointing for Harriet, but, understandably, she became angry about what she perceived as repackaging and the exploitation of herself and others:

“I thought that’s ridiculous ... [] they’re presenting it as something new and people have been taken in by it”. (Harriet: 1174-1183)

As we might imagine, it seemed Harriet’s trust in the MBI organisers or developers was damaged. She described guessing at the agendas behind the exercises she felt confused by and thinking the worst. Part of Harriet seemed to conclude that underlying the course was the assumption that individuals were fabricating the nature or severity of their condition:

“What’s the point of it? [] Are they trying to get us fitter because we’re quite out of condition?” (Harriet: 1305-1308)

For two participants, Richard and Harriet, scepticism seemed to be a part of their identity that they could not switch off. Richard said:

“My main personal characteristic is this sceptical one. I think in some ways it’s kind of preventing me from totally accepting it [mindfulness] as a philosophy and perhaps getting more out of it.”  
(Richard: 1837-1846)

There seemed wistfulness in Richard's account, a yearning to let go of his scepticism and reap the benefits he saw others on the course experiencing. Likely based on his observation of his course peers, Richard seemed to believe that if one could truly give oneself to mindfulness it might dramatically change one's life. Richard talked of a way he might be able to put more faith into the techniques:

"I would like to have a better intellectual understanding of the evidence for its benefits, so that I can put that against my personal experience of it, and perhaps enrich it, and say well, you know, there is good research evidence for doing this therefore I should apply more." (Richard: 1861-1874)

Richard seemed to be ignoring his personal experience that he found, and continued to find, some of the techniques unhelpful. In a sense, Richard appeared to appraise his experience and what his body was telling him as unimportant. Instead, I feel Richard was searching for an academic "truth", a truth which advocated mindfulness and one in which he could believe more than his own personal experience.

Harriet espoused a similar experience. She too spoke about scepticism as part of her identity and she described questioning whether her facilitator and peers were experiencing a placebo effect:

"They just seem to believe so wholeheartedly that it will help them and it has [] and you think, well I don't know what came first." (Harriet: 503-508)

She questioned also whether timing was a mechanism of change:

"It just changed her life, you know. It made a huge difference, and part of me thinks, ah, it was just the ri- it was just that particular time, wasn't it." (Harriet: 455-461)

Like Richard, Harriet seemed to subscribe to the belief that, if one could truly give oneself to mindfulness, it might make a huge difference to one's life. Again, contained within Harriet's account is a sense of wistfulness. It seemed Harriet wished she could put faith in mindfulness the way she perceived others to, because she desperately desired for herself the benefits others seemed to have gained:

"I blame myself, and think if I'd done that it might have helped me more". (Harriet: 509-512)

It appears quite clear that facilitators had an enormous influence on individuals' perception of mindfulness and its potential. In the following section we look more closely at the facilitator as a barrier, considering how facilitators' guidance and delivery impacted individuals' understanding of and engagement with the material.

### **3.4.2 Facilitator-related barriers**

Six participants spoke about the facilitator acting as a barrier. Whereas Daniel reported later that his pondering about religion was unfounded, Harriet described a different experience:

"She'd end with saying 'amen' and put her hands together. Now that unnerved me slightly because I thought, 'does she mean amen in a sort of Buddhist type thing?' [] it confused me as to where she was coming from and what sort of course it was." (Harriet: 2240-2255)

Harriet felt uncomfortable, wondering whether her facilitator was trying to engage her in a Buddhist act. She described not joining in with the "amen", and noting whether other members of her course did the same. We see that throughout much of the course, Harriet's attention was focussed away from actual engagement with the practices. It is reasonable to assume that Harriet's compromised concentration (due to her ME/CFS) and the belief that she had tried the techniques before fed into

this disconnection. However, it certainly seemed that the facilitator's guidance and delivery led to this disunion also.

In questioning the religious agenda behind her facilitator, Harriet seemed to perceive her facilitator's agenda as one not focussed on the client. Caroline also doubted whether her facilitator's intentions were driven by the needs of the participant. She spoke about perceiving her facilitator to prioritise time above the capabilities of her students:

"Sometimes the person on that side is just governed by a clock, or a period of sessions, and that's not the way it should be because that puts you, instantly you [feel] like you've got to deliver [] and you can't just deliver it like that." (Caroline: 1348-1356)

Caroline explained that, in her quest to perform for her facilitator, she was unable to use exercises in the way she wished. Caroline appeared to refer to the body scan. In particular, she described being unable to spend the time she wanted exploring particular body parts. She reported being unable to be with them as they were, instead feeling pressured to experience something specific:

"You think, 'right, I've gotta feel this in this toe'". (Caroline: 1374-1376)

It seemed that contrary to what is advocated by much of the mindfulness literature, Caroline was not observing with an attitude of curiosity. Rather, she was seeking with a narrowed and expecting perspective.

Participants also talked about the guidance their facilitators gave them and how this could act as a barrier or an enabler. Harriet talked about not connecting with the metaphors her facilitator spoke about, lacking understanding of the concepts behind them:

“She sort of had techniques that you’re supposed to think of, like water and things. [] But, I felt once we’d been given the idea it was just left and we weren’t quite sure how to apply it.” (Harriet: 248-255)

It seemed Harriet had felt some instruction was missing – “it was just left”. Harriet appeared to feel she lacked guidance on how to apply the theory that the class had been introduced to. Patricia espoused a similar experience. In the absence of guidance she could connect with, Patricia described referring back to particular readings and attempting to literally act the metaphors she had read about:

"I remember once reading something that said ‘meditation is the spaces between the words’, so I would have this phrase ‘meditation is the space between the words’ going through my mind, and I would try and stick on the spaces between the words." (Patricia: 1884-1894)

Rather than helping her connect with what she now understands as meditation, Patricia described being confused by the metaphor. She explained that she found it would take her away from the meditative process of focussing on her body and the present moment. Patricia described persevering with mindfulness and eventually finding teachers who communicated the process in language she connected with. From her position of hindsight, Patricia was able to clearly state that initially she did not understand what she was trying to do. She was stuck trying to do something but unsure what this was. It seemed that Patricia understood the instructions she was or was not given as the gatekeeper to conducting mindfulness properly:

“I’d be doing what they said, but it didn’t, they didn’t give me instructions that made that shift for me.” (Patricia: 1585-1590)

Caroline spoke about a lady on her course that seemed to experience similar. The instruction of “bring [your mind] back” when it wandered was insufficient for her to understand how to carry out the process:

“There was a lady just to my right [] she didn’t understand certain elements of this, you know when your mind drifts just bring it back, ‘well how do I just bring it back? I don’t know how to bring it back’.” (Caroline: 240-245)

It seemed that similar to Harriet and Patricia, this lady needed more. She appeared to require some explanation of what the bringing back process looked like. Indeed, Patricia explained that once she learned being mindful could mean focussing on one’s breath in one’s stomach, her understanding of the mindfulness process started to fall into place.

It appears obvious that facilitators played a pivotal role in participants’ accounts of their MBIs. We will re-visit the influence of facilitators later. Before then, in the next sub-theme, we explore how vital it seemed to individuals to manage their symptoms and avoid significant exacerbation of these. We take some time to consider this topic here as it lends important background to later considerations concerning facilitators and peers.

### ***3.5 Master theme three – The vulnerable self - “It puts you on a back foot before you’ve even started”***

Many participants gave accounts of feeling unsafe or unprotected. It is for this reason that the third master theme is entitled ‘The vulnerable self’. Feeling unsafe was often connected to two factors – the precarious nature of symptoms and stigma towards the condition. We start exploring participants’ vulnerabilities in *The imperative of symptom management*, where we gain insight into how participants managed the threat of symptom exacerbation around the course as well as how

important this management was for them. We also learn about participants' anxieties around symptom exacerbation generally and the role that MBIs were understood to play in this context. Then, in *Expecting the worst*, we encounter accounts of nervousness whereby participants anticipated little understanding from others and in some cases, ridicule, as a result of having ME/CFS. It appeared that participants' expectations of how others might respond to their condition (and to themselves as a result of having ME/CFS), left individuals feeling vulnerable and at risk.

### **3.5.1 The imperative of symptom management**

All eight participants spoke about symptom exacerbation and at least six appeared markedly anxious about symptoms worsening. For these participants, not deteriorating and protecting against deterioration appeared essential, with individuals describing a constant state of vigilance. Participants appeared to be in a vulnerable position, as symptoms were reported to be easily exacerbated by physical and mental activity. Individuals described experiencing significant limitations as a result of their symptoms, constraints which affected their social lives, relationships and employment.

Participants' MBIs, as activities which included physical and emotional activity, were not exempt from heightening or inducing symptoms. Irv described his symptoms being made worse simply by travelling to his MBI. He reported that he "wasn't up to" travelling by bus as he anticipated this would induce fatigue and days of bed rest. In particular, Irv noted the amount of time spent on the bus, the noise, and possibly being required to chat to his fellow passengers as possible triggers for symptoms. In order to attend, and in the absence of owning a car, Irv was forced to over-exert himself by riding his motorcycle. This resulted in him being "wasted" when he arrived:

“Getting there would have been three buses, which I wasn’t up to. I didn’t have a car. I still had my bike so I was going on my bike, but I wasn’t really well enough to ride my bike, so when I got there I was wasted.” (Irv: 715-722)

Arriving to the course “wasted” meant Irv reached the venue feeling exhausted and with impaired concentration. To recuperate enough to engage in the session, Irv developed the following strategy:

“I’d go a bit early, maybe 20 minutes, and just lie on a mat”.  
(Irv: 728-730)

Irv talked about being very aware of the possible detriment the sessions could have upon his health. The potential for his symptoms to worsen appeared to cause him much anxiety. He described a vivid fantasy of being ill after sessions and strongly desiring this not to occur:

“It would be [] straight back in, everything off, maybe a bath and then straight into bed, or just collapse on the bed, erm and that would cause me a lot of anxiety, cos I don’t want to be ill, I want to try and stay away from ill [] that was my anxiety [] that I had a price to pay for this.” (Irv: 938-949)

As we can see, Irv described being extremely anxious as a result of considering how his symptoms might be worsened by the MBI sessions. Harriet’s account was somewhat similar. She spoke about going to great lengths minimise her activity around the course, with the aim of reducing its impact on her symptoms:

“When you’re trying to pace and everything you’re aware that Tuesday afternoon is that course, and that has a big impact on what you’re doing on the, you know, what you do on the Monday. Sort of psyching yourself up to it and making sure you’re well-rested and everything. And then just nothing

on the Tuesday before you go, having nothing on in the evening and hopefully not having anything on the Wednesday.” (Harriet: 1635-1652)

As well as giving a clear account of physical preparation, Harriet alludes to mental preparation, a process of “psyching [herself] up” to the sessions. In my opinion, Harriet’s dramatic reduction of activity and this process of “psyching” indicates an underlying anxiety. It speaks to me of fear and a powerful commitment to health. Indeed, elsewhere Harriet described refusing possible social engagements and potentially postponing doctors’ appointments in lieu of the course. Rather than two-hour appointments, each mindfulness session became a three-day cautionary period.

We can understand why such caution was imperative to Harriet when contemplating the considerable impairment that pushing herself past her limits afforded:

“I do get a really bad headache [] you do think I just can’t wait to get home, and sometimes you can’t even make a cup of tea. You just have to get straight into bed. So there’s the sort of immediate aftermath of it that you’re so tired, and then [] it often is a residue that goes on to the next day or longer than that.” (Harriet: 1763-1780)

Harriet’s heightened symptoms prevented her from completing even small tasks, such as making a cup of tea on returning home. Rather, she required immediate bed rest. We see that, as we know to be normal for many with ME/CFS, Harriet took longer than others might to recover from the activity, resulting in a prolonged period of limitation, a “residue”. As well as affording us insight into the aftermath of the sessions, Harriet’s interview painted a picture of the detrimental impact of sessions on symptoms in-situ. It seemed Harriet’s symptoms were at a manageable level

when she arrived, but would become heightened and overwhelming during the length of the session:

“Two hours I can feel I’m absolutely wilting ... you’re just not concentrating anymore and you just, sometimes I’m actually literally falling asleep, erm you know, holding a pen.”  
(Harriet: 684-698)

It appears clear that it is the session, the “two hours”, which induced this “wilting”. This suggests that after a certain point, sessions became more of a hindrance than a help to Harriet. She could not concentrate on the material and as evident in her extracts above, experienced a reduced level of functioning for days afterwards.

Whereas Irv and Harriet worried about the impact the course might have but attended anyway, Lucy made a different decision:

“I signed up for courses with them before and I ended up cancelling cos I just thought ‘I can’t make it’.”  
(Lucy: 304-307)

Lucy’s fear of travelling and the impairment she anticipated the journey to cause meant she avoided attending altogether. It seemed the image of not making it overrode her desire to attend. To her it was essential to ensure that what was feared to happen did not occur. Lucy later accessed the course when it became available in her area.

As well as attendance, Lucy gave insight into what else might induce her symptoms and of what she wished to avoid. She spoke about her concerns around digestive symptoms:

“There was also a bit on mindful eating [in the course]. [] I was a bit kind of against that because I’d normally, like, take

digestive enzymes and stuff, and I just thought 'oh no'."

(Lucy: 1327-1334)

Elsewhere, Lucy explained that she took these enzymes to avoid swelling and pain in her digestive system. The words "oh no" give insight into the depth of Lucy's dread, as if she was panicking about the exercise. The potency of Lucy's fear can be deduced from the position she speaks from as, even in our interview conducted years after the event, she connects herself with the feeling at the time – "oh no". It seems Lucy's fear led her to shut down. She described herself as "against" the eating practice, suggesting she had closed herself to the idea, erecting a protective barrier.

As well as worrying, reducing activity, and avoiding attending, participants' vigilance towards preventing symptom exacerbation seemed to manifest in a constant state of assessment. The following extract from Daniel's interview embodies what was present in many participants' accounts. In particular participants spoke about assessing the length of sessions, breaks, mixing activities, the energy involved in activities, and subsequently related this to symptom exacerbation or manageability. Daniel said:

"I can't remember how many hours it was now but I know I found it okay at the time. But a lot of that was because we had breaks [] and er also you did a lot of lying down, body scans and that, so it was, yeah, it wasn't too difficult." (Daniel: 559-577)

We can see that having ME/CFS automatically placed participants in a position perhaps more vulnerable than if they did not have the condition. As a result of this vulnerability and the significant impairment their conditions afforded, the importance of preserving functioning and thus engaging in a process of symptom management appeared heightened.

This story is not one particular to symptom management in and around MBI sessions per se. Many participants' accounts were peppered with the imperative of such management in terms of the course as a whole. Improving one's symptoms and situations appeared essential and again it was as if participants had developed vigilance toward this. For Harriet, Lucy and Caroline, attending the course appeared to be a strategy employed in the hope that symptoms would improve. As Harriet said:

"I should be more realistic, but you really hope that each time it's going to be the one thing that gives you loads of energy and helps you hugely." (Harriet: 113-119)

Against her better judgement, Harriet hoped that the course would grant her the energy and change she longed for. She spoke about completing all the home practice and 'homework', despite believing that she had tried all the techniques before, to no avail.

Participants appeared to frequently assess whether things were 'working'. As Lucy said:

"I almost didn't go cos I thought this isn't really going to help". (Lucy: 184-186)

In Lucy's mind, it seems the only point of attending the course was for it to help her ME/CFS. Caroline's account was the same:

"I probably would have dropped out if I hadn't have got any information on mindfulness or relaxation, or I hadn't got the yoga background [] I'd have dropped out because I'd have just said that this was a complete waste of time, and I would have just dismissed mindfulness altogether." (Caroline: 630-638)

Caroline's previous experience gave her insight into what she understood the intervention to be aiming towards, without which she said she would have "dismissed mindfulness altogether". There is certainly the sense that mindfulness was expected to *do* something, to work in some way.

We can see that ME/CFS was the lens through which participants continually viewed the courses and material. This also seems true of how participants' perceived themselves. Evident within individuals' accounts appeared a palpable fear of being judged based on their illness. This is explored in the next sub-theme.

### **3.5.2 Expecting the worst**

Three participants spoke about engaging in a process of worrying, whereby they anticipated their peers or facilitators judging them and not understanding their conditions. These fears appeared to be rooted in experiences outside of the course, where people had found others to be disparaging or ignorant as regards their ME/CFS. Harriet described hiding her illness in everyday life, even from her friends:

"I don't tell very many people [] for fear I'm judged." (Harriet: 783-789)

Harriet explained that some people outside the course did not believe she was ill. This gives insight into what she feared being judged on during the course – the legitimacy of her illness. It seemed that having an illness perceived as fabricated placed Harriet in a position where she felt required to defend her lifestyle. This seemed to elicit much anxiety and she spoke about automatically panicking in response to being asked about work:

"They say 'do you work' and for a split second I think 'oh gosh I'm going to have to come up with an excuse again'."  
(Harriet: 797-801)

By suggesting that she usually “come[s] up with an excuse”, Harriet indicated that in other situations she had not found the “excuse” of having ME/CFS sufficient to explain why she did not work. Irv espoused a similar experience. He talked about being required by people outside of the course to explain himself and give reasons for why he was restricted by his illness. Irv described being almost despairing, saying he had run out of excuses and was “just ill” (line 745). Irv explained that he expected his peers on the course to treat him in much the same way. Similar to Harriet’s account, Irv reported that imagining people on the course being insensitive to his symptoms elicited anxiety for him:

“I just was expecting everybody to be very negative, or nonchalant if you like, as to what you felt like, so I was anxious about that.” (Irv: 898-903)

Lucy also spoke about experiencing stigmatising responses from others outside of the course in regards to her ME/CFS. Again she talked about feeling anxious before and somewhat during the sessions. For Lucy, it was the strangeness and uniqueness of her condition which elicited anxiety:

“To go into a group of, I dunno, 10 or 11 people, with a pretty weird condition, em, I didn’t feel that confident initially.” (Lucy: 1059-1064)

Caroline and Patricia also recounted experiencing incredulity from individuals or organisations outside of the course in terms of their conditions. Like Irv, Harriet and Lucy, Caroline and Patricia explained that the validity of their illnesses had been strongly challenged, either by their peers (outside the course), family, work, or the Department for Work and Pensions.

It was not just the anticipated responses of peers that elicited anxiety in participants. Facilitators also appeared to hold significant power over the sense of nervousness

or safety individuals experienced. This seemed implicit in at least six accounts. Power to elicit anxiety appeared closely connected to facilitators' agency over the sessions, specifically to their ability to request activity which might heighten symptoms. Extracts from Irv's interview paint a clear picture of feeling vulnerable when anticipating that facilitators might ask for more than he was willing or able to give:

"One lady [] she was quite forceful in her demeanour, and quite positive, and this is gonna happen [] the other lady came in and was just the calming effect [] her demeanour was lovely, very gentle [] had she not been there it would have made me feel anxious." (Irv: 514-550)

Irv explained that, at the time of the MBI, his self-esteem was extremely low. I hypothesise that at the time he would not have had the courage to assert himself and request to sit out of any activity he felt was particularly detrimental. He was in a vulnerable position. It seems to me that the other facilitator provided a "calming effect" for Irv because her "lovely" and "gentle" demeanour felt more approachable to him.

It seemed the same anxiety regarding heightening symptoms was present for Irv in his assessment of his facilitators' dress. He reported evaluating their dress in terms of what activity it might connote, and finding the clothes containing:

"There was nothing about it that made it feel 'oh my goodness, what're we gonna do', you know, backflips and handstands, you know, it was very gentle, the appearance of it all." (Irv: 662-669)

Just before this excerpt, Irv explained that his facilitators were wearing loose trousers and comfortable t-shirts. Rather than "backflips and handstands", Irv described the dress to connote gentle, and thus manageable, activity. As Lucy

described earlier, Irv's account suggests that a requirement to complete activity likely to make symptoms worse would have been met with panic – "oh my goodness".

Overall, it appeared that no participants found their peers or facilitators to lack understanding of their condition or to take a stigmatising attitude towards it. Instead participants reported quite the opposite, finding that their fears and anxieties were quelled by the flexible and understanding attitudes of both peers and facilitators. The sense of containment this gave to participants as regards their vulnerabilities is explored in the next master theme.

### **3.6 Master theme four - Healing relationships – "It healed a lot straight away"**

This master theme considers the relationships participants encountered during their MBIs. We look at the positive aspects of these, in particular how relationships helped to ease anxieties and spark growth or change. In *Validation and belonging*, we look at what it was like for participants to meet others who encountered them with acceptance and understanding. We explore how individuals' found it to share their experiences and learn about the experiences of others, as well as what it was like to feel part of a wider group. Then, in *Hope and engagement* we consider how relationships with peers and facilitators cultivated a sense of optimism for participants, as well as helping them to engage with the mindfulness material.

#### **3.6.1 Validation and belonging**

As we saw in *The vulnerable self*, Lucy, Harriet and Irv described feeling anxious and unsafe before and during their MBIs. They described fearing negative responses from their peers and facilitators as regards their illnesses and the constraints these placed upon them. All three participants described this initial nervousness diminishing during the course. Rather than exacerbating anxiety as expected, peers and facilitators were generally found to contain and reduce unease

around energy expenditure and potential prejudice. Much of this containment was related to learning that others understood and respected their condition. Earlier we saw that Harriet panicked when thinking she would have to create an excuse for why she did not work. In the extended quote below, we see that Harriet found it “quite a relief” to meet people whom she perceived to understand her:

“When I go to something like this it’s quite a relief [] they say ‘do you work’ and for a split second I think ‘oh gosh I’m going to have to come up with an excuse again’, and I think ‘oh hang on, they know’.” (Harriet: 795-802)

It seems that Harriet’s initial panic subsided as she realised “they know”. Harriet seemed to suggest that not only did individuals know that she had ME/CFS, but they knew what this was about and understood that some people with the condition cannot work. There is the sense Harriet believed that not only did people understand, but they accepted it and, by extension, accepted her.

Irv espoused a similar experience. Like Harriet, Irv’s experience of his peers on the course appeared to be in direct opposition to past experiences whereby individuals had questioned the legitimacy of his illness:

“I was with people who, we didn’t have to explain anything, we just didn’t mention it, so that in itself was [] good.” (Irv: 1472-1476)

It seems for Irv, as it was for Harriet, it was the lack of pressure to explain and the implicit sense of being understood that was containing. There was a sense of surprise in participants’ accounts at the understanding and acknowledgement they encountered from their peers. As Harriet espoused:

“If you’re having a really bad day, and you’ve just sort of poured yourself out of bed, [] anywhere else you’d be worried if people

think 'blimey she looks awful'. But they think, 'oh she looks awful but she's managed to get here'. And that's quite a big difference."  
(Harriet: 868-879)

As Harriet spoke I sensed much warmth in her voice. It was almost as if she was reliving the experience of feeling accepted and of having one's achievements recognised. Shortly after, when speaking about taking medication, Harriet put the warmth I had felt from this earlier account specifically into words:

"If you have an awful headache and, you know, at the break you get your Paracetamol out. Again, people are just, there's just a warmth really, that people are quite understanding." (Harriet: 880-887)

This sense of understanding and acceptance appeared to be a rare occurrence for Harriet. It seemed something delicious, to be savoured and enjoyed. Similar to Irv and Harriet, Caroline also spoke about finding it unnecessary to "explain or excuse" herself or her symptoms:

"It was just chatting and having that conversation with people who, you don't need to explain or excuse yourself if you yawn half-way through a sentence. Cos people understood that it's not personal." (Caroline: 734-740)

Caroline shows us that what might have been perceived as rude by people with little knowledge of the condition, was recognised for what it was, a consequence of having ME/CFS. More than just an understanding that went no further, Caroline told of how such occurrences provided amusement between the peers on the course:

"If somebody's starting a conversation, and they get half-way through, and they've just lost it. You all have a laugh because we've all been there." (Caroline: 740-744)

We can see from the phrase “we’ve all” that Caroline positions herself as part of the group. There appears a great sense of shared feeling, of individuals laughing because they experienced empathy for the other. Similar to both Irv and Harriet’s accounts, it was as if, recognising in one’s peers elements of one’s own experience, participants felt a special connection with the other course members.

Similar to participants’ accounts of their peers, facilitators appeared to be found containing when they showed understanding of the illness. Specifically, facilitators were found validating when they exhibited awareness about what might heighten symptoms, and an attitude of prioritising symptom reduction. As Irv said:

“They spotted it straight away, it wasn’t like ‘oh, what’s the matter with you then’ [] it was ‘do you need to lie down’ [] and how nice just to be accepted straight away, not ‘well you should have got the bus’ or ‘you should have done this’, it’s ‘oh no worries, come in and lie down, that’s fine and don’t worry’ [] I just thought that was, takes that pressure off.” (Irv: 723-740)

As discussed earlier, it appears evident that Irv felt “pressure” on arrival to the course. This pressure seemed to be alleviated by the facilitators’ non-judgemental and accepting reception and their sensitivity to Irv’s needs. Communicating that they wanted him to feel comfortable, “no worries [] don’t worry”, seems to have added to this easing of his nerves. Lucy described a similar experience. She spoke about her initial anxiety diminishing when she learned that her facilitator was sensitive and flexible:

“She was very willing to try and help you erm and also very aware when you do the practice that some people were better sitting up, some lying down [] basically you could do what you wanted [] so I found I was relaxed in her presence because she

was very flexible, she wasn't rigid in her ways." (Lucy: 1007-1020)

As well as enjoying the feeling that their conditions were automatically understood, participants spoke about the therapeutic nature of sharing their struggles. Harriet described it as "nice" for her to share some of her difficulties with the group:

"It was quite nice [] being able to talk to somebody about these bikes that I was struggling with". (Harriet: 1372-1376)

It seemed that what Harriet gained from sharing was made all the more special to her because she felt unable to share with other people in her life. She explained:

"I'm not very open with my other friends. [] You can't say, well actually I'm not very well and it's an enormous struggle, cos I've chosen not to tell them. [] So you can't expect sympathy. [] But it is nice when people do realise." (Harriet: 1394-1412)

Harriet's choice not to tell others about her illness restricted the support she could gain from them. Feeling able to talk about her difficulties meant Harriet's struggles were recognised in a way they were not outside the course. It was "nice" for Harriet to feel these were being seen and to gain sympathy regarding them.

Caroline also spoke about how she found talking to others about her experiences to be positive. For Caroline, it seemed that conversing with others in a similar position changed her perspective and meant she stopped blaming herself for being ill and the limitations this had placed on her working life:

"It's the company that's wrong, you're not wrong. And that lifted a weight off my shoulders cos I thought it was all my fault. [] You can feel like that when you keep going back to the GP and they're not supporting you. So actually speaking to other people

who are in the same situation, you think, 'do you know what? No, it's not me. It's actually you'." (Caroline: 817-826)

It seemed Caroline found validation in her interactions with her course members that had been missing from her GP and previous workplace. As a result, Caroline appeared relieved, less burdened by the idea that the fault of the matter lay with her. Caroline explained that talking to others was also helpful because it led her to realise she was not alone in her thoughts and emotions:

"It's very helpful to talk to other people because it can be very isolating, and you can think, 'am I the only one in the world that's feeling like this?' And actually, when you talk to other people you realise that other people are feeling the same." (Caroline: 688-694)

Irv also learned on the MBI that others felt the same as him. He spoke about the effect this had:

"It wasn't just me, erm, you know, feeling guilt. [] You do when you're ill. [] You're not the dad you should be. You certainly weren't the husband you should have been. [] So, it started to break those down a little bit." (Irv: 1479-1492)

It seemed that throughout Irv's illness he had developed beliefs about not being good enough and engaged in self-criticism regarding these. Learning that others felt guilt too started to change his beliefs and somehow lessen his guilty feelings.

Like Caroline, Nadia also talked about being isolated due to her illness and the limitations this placed upon her. Rather than a work context, Nadia referred to fitting in with her family and friends, where developing ME/CFS had resulted in her feeling the "odd one out". There is a sense that Nadia felt comforted from knowing there

were others “out there” in close proximity, experiencing the same emotions and struggles as she:

“I’ve enjoyed knowing that there are other people in my local vicinity [] that there’s similar-minded people out there, and that what I’m feeling most of the time won’t be any different to what they’re feeling, you know, what they’re struggling with [] ... it’s the normalising [] you feel very isolated, especially because your activities and your energy is limited, so within your normal group of friends [] or your family [] you constantly feel like left out or that you can’t join in or the, you know, the odd one out. [] It’s [the course is] an environment that encourages you that you’re not the odd one out.” (Nadia: 489-523)

Nadia described the course as a normalising environment, one which reduced her sense of isolation at the time of the MBI, as well as affording her comfort after it had finished. We can see from Nadia’s quote below, just how important that normalising process was for her:

“It was just nice, it normalises it. That’s the importance of it. And I think that’s what I kind of miss a little bit now.” (Nadia: 475-479)

Overall, we can see that at least five participants found benefits from their MBIs that went above and beyond mindfulness input. For these individuals, being with peers who experienced the same difficulties and acknowledged them in the other was a powerfully therapeutic process. In the next sub-theme we continue to consider the healing impact of facilitators and peers that reached beyond the standard mindfulness material. We explore how the other people present on the course influenced participants’ sense of hope, and their engagement with the mindfulness theory and practice.

### 3.6.2 Hope and engagement

Themes of being open to and engaging with mindfulness appeared present for at least seven participants. Individuals described various factors hindering their ability to engage with practice. As we saw in ‘Struggling with doubts and understanding’, personal scepticism and confusing guidance acted as barriers to engagement. Participants also spoke about obstacles centring around the type of venue (e.g. a hospital), its temperature and appearance, and outside distractions such as chores or work-site noise. Richard and Lucy gave accounts of how interactions with others on the course helped overcome some of these hurdles. For Richard, a sense of social obligation meant that he opened up to mindfulness and allowed himself to be affected by it in a manner he might not have at home. He said:

“There’s a big advantage to the fact that you’re in a group ... [] there’s a kind of group mentality, we’re all in this together, you’re not going to stand up in the middle of it [] it’s disruptive to the group if you suddenly then want to get up [] I think that’s a positive thing because it means that you’re giving [] it an opportunity to, you know, giving yourself an opportunity to see wh- it’s effects and what it can do.” (Richard: 1233-1285)

Richard interrupted his sentence – “you’re giving [] it an opportunity to [] giving *yourself* an opportunity to”. In doing so he placed emphasis on the idea that being in the group allowed him to give him, as well as mindfulness, an opportunity. It seemed that Richard’s sense of comradeship, namely his obligation to the concentration of others, helped him overcome some sort of internal barrier to the practice.

Lucy espoused a similar account. Her observation of and interaction with her group facilitator helped to open her up to trying mindfulness. She said:

“I think it helped, knowing that she had a condition, and she was using this mindfulness”. (Lucy: 925-928)

As we saw earlier, before the course Lucy was mostly convinced that mindfulness was not going to help her. It seemed that finding out about her facilitator’s use of mindfulness and learning how her facilitator had used mindfulness to greatly improve her quality of life, helped Lucy to open up to the idea that it might have potential for her too:

“I just kind of felt, if she can make such a difference then maybe it might help me”. (Lucy: 983-986)

As well as her interaction with her facilitator, Lucy described being particularly influenced by an encounter with one of her course peers:

“He came in one day with awful pain, and I just looked at him and I thought, ‘I don’t, why have you come in today’ [] after about an hour he said, ‘oh, he was beginning to feel much better’, and then he could move more easily [] that was like penny dropping.”  
(Lucy: 766-787)

It seemed that at the beginning of the session, when empathising with her peer’s pain, Lucy struggled to comprehend why he had “come in”. Lucy appeared to suggest that should she have been in his position, she would have stayed at home. I believe this indicates that Lucy believed staying at home was the best way to deal with the pain and manage the situation. It seems that as her peer’s pain subsided and he became less physically restricted, Lucy had a moment of realisation whereby her beliefs shifted. Perhaps attending the session was the best decision for him after all. From this changing perspective appeared hope, as it really hit home that mindfulness could give her some control over her symptoms:

“I felt mentally better cos I thought, actually whilst I can’t get rid of the symptoms, I can, you know, improve it.” (Lucy: 815-819)

Harriet gives us insight into relationships and hope from the other side of the fence. She described comparing herself to her facilitator and finding a tangible sense of dissimilarity. Whereas for Lucy the commonality she found with her facilitator gave her hope, it seems the dissimilarity Harriet found with her facilitator took it away. Harriet seemed to foster a belief that she, as a less “organised” person, could not practice mindfulness every day and, by extension, could not experience the same benefits as her facilitator. She spoke of this almost like a reality check, the hope she had built during the course dwindling as she returned to her “own life”:

“When you come back to your own life, and as I say hers sounded very organised and everything [] I feel like there’s no way I can replicate that [structured home practice] really.”  
(Harriet: 322-328)

Caroline also talked about difficulty engaging with the material. She explained that a gentleman on her course appeared visibly frustrated as a result of not understanding what he was supposed to be doing. Caroline spoke as if she resonated with his experience. In each context, both for the gentleman and for her, Caroline stated that talking this through with others on the course was a ‘helpful’ endeavour:

“You think, ‘well, am I the only one who’s not getting it?’ [] He was getting very frustrated and actually it helped him when he realised, ‘oh no, we’re all feeling it’.” (Caroline: 711-716)

There appeared a sense of kinship in Caroline’s account. She spoke as if she and her peer experienced a process of normalisation which was beneficial in some way. Shortly after, Caroline spoke about the facilitator’s guidance being poor and it was

as if, knowing that the problem lay externally to the individual, something changed. There seemed to be a sense that it was not mindfulness failing to 'work', but an issue that lay with it not being applied in quite the right way. It is my opinion that this belief would have made participants more likely to re-engage with the exercises, their faith in mindfulness' potential restored. Indeed Patricia spoke about this very process, her awareness that she was confused allowing her to remain hopeful and continue trying to meditate.

After the interview had finished, Caroline explained that she had been encouraging her friends who had previously been 'put off' mindfulness, to re-engage with it. It seemed that, in being able to explain to her friends that she had also felt frustrated and disconnected with mindfulness, she was given a kind of credibility. As a person who had 'been there', she was able to say "try it again".

Above I have focussed on how relationships affected engagement and on how relationships influenced hope relating to the potential of mindfulness. Irv spoke about relationships and hope too. For him, social encounters on the course were found to offer optimism for the future. Similar to Lucy's experience detailed earlier in this section, Irv's experience of the course appeared to elicit a change in his belief system. For Irv, the relationships he built on the course allowed him to see a different potential for his life and his time to come:

"That was the glimmer of hope [] that actually made me feel there's more to life than just ME and being stuck by yourself in your own four walls, you know, there's something else out there."

(Irv: 1841-1853)

Irv explained that part of the "something else" he had found was connection and friendship with others. He spoke about maintaining a friendship with one peer post-

course. It seemed that socialising on the course allowed Irv to see that his life no longer needed to consist solely of isolation and illness.

### **3.7 Summary**

Individuals gave complex reports of MBIs which encompassed both positive and negative accounts. For some, mindfulness gifted acceptance, ways of self-soothing and methods of re-gaining control. Individuals talked about being able to make adjustments needed to manage their symptoms as a result. Further, participants said they were prevented from sinking into low mood, being able to distract themselves from the thoughts which caused this as well as modify the content of contributory cognitions. Pain was made less distressing too.

Participants spoke about struggling with mindfulness, particularly with understanding the material and with setting aside doubts and uncertainties. The majority of participants reported initial hesitations, some about whether mindfulness had the potential to help them or to 'work'. The simplicity and religious orientation of the techniques were questioned and for one participant, Harriet, mindfulness appeared to her as a façade. It seemed to be relaxation, covertly presented as a new and original intervention. For some, a perceived inner propensity toward cynicism was encountered as a drawback, hindering full commitment and the imagined resultant benefits. Facilitators appeared to play a significant role in individuals' struggles with mindfulness. Feeling pressure from them to perform or being confused by guidance were obstacles preventing a more positive experience.

For many individuals, being at the MBIs was experienced as placing them in a vulnerable position. As illness was exacerbated so easily, the need to manage this appeared imperative. Any exercise or person with the potential to be detrimental to symptoms was approached with caution, and found to elicit anxiety within participants. Travelling to the MBI, engaging with the material and exercises whilst

there or just simply attending, were all reported to impact symptoms. As a consequence, these elements carried with them a feeling of danger. They were, in a sense, a threat. Many participants spoke about their expectations for the course and some appeared to anticipate the worst. Participants' past experiences of ignorance or denigration toward their condition appeared to have left individuals fearing judgement from others. Individuals expressed worrying about being persecuted regarding the legitimacy of their illness, their ability to work and their needs in relation to managing their symptoms. They also described fearing that peers and facilitators would show little understanding of the illness, placing them in a situation where they would need to be assertive and self-confident. It appeared quite clear to me that having ME/CFS left individuals feeling they were in an extremely vulnerable position.

The vast majority of participants' fears appeared to be unfounded in the context of the course. In fact, the relationships and social encounters individuals experienced were frequently described as completely opposite to their initial expectations. Further, these relationships appeared to hold healing qualities. They provided a sense of validation, belonging and hope, as well as positively influencing participants' engagement with the mindfulness material. It was a relief to meet people who understood their condition and the limitations this placed upon both individuals' lives and their capabilities. It felt good to have people acknowledge triumphs that others might completely miss. When shared symptoms arose they provided humour. Moreover, speaking to others about difficulties provided a sense of inclusion and affirmation.

Being in the presence of others was reported to increase individuals' motivation to practice mindfulness. The group was said to provide a context where one would stay lying down for longer to avoid disturbing others. The situation also provided a space more removed from distracting household chores. Seeing mindfulness

benefit others appeared to provide a sense of optimism, borne from the belief that it might be able to help participants too. When difficulties with engagement occurred, knowing that one was not alone in struggling with the exercises provided a sense of being normal. This appeared to act as encouragement for trying again.

In the next section, it is considered what these findings might mean for us as counselling psychologists. How do these findings fit into the existing literature? What does this tell us about best practice when delivering interventions? How might we use the findings to provide input most likely to be helpful to individuals with ME/CFS?

## 4. Discussion

As we have seen, participants in the current study scrutinised the attitudes of others towards ME/CFS. The attitudes others were perceived to hold were particularly influential in how the person with ME/CFS conceptualised themselves, and how they conceptualised the individual holding that attitude. This appears representative of the general field, as individuals' attitudes towards ME/CFS and the effects of these are frequently considered in research (e.g. Dickson et al., 2007), by patient organisations (see the 'Controversy' section of the MEA, 2014) and social media groups (e.g. Moss-Morris and Petrie, 2000). Therefore, I believe it apt to begin this discussion by explaining my own positioning in a short reflexive account. Following this, I shall consider what I have termed 'the ME/CFS lens', and explore stigma and its manifestation in participants' experiences. I then discuss therapeutic relationships both within the peer group and between facilitators and clients, talk about acceptance and coping, and review working with scepticism, cynicism and doubt. The implications of each aforementioned area to conducting future MBIs are considered. As well as mindfulness, ACT in particular is highlighted as a potentially useful intervention for individuals with ME/CFS. Succeeding this, I discuss methodological considerations and make suggestions for future research.

Due to space limitations, I decided to deliberate the chosen areas. I believe other facets of the analysis are also worthy of discussion and intend to address these in further papers. Other papers may focus on the preciousness of life and time, values and the experience of these, and self-criticism and self-blame. Mindfulness and control, transience, and repackaging and disappointment could also be worthy of further discussion.

#### ***4.1 Reflexivity and position statement***

I grew up heavily subscribing to the view that ME/CFS is solely of biological aetiology. During this time, I witnessed stigmatising attitudes from colleagues, friends, and other family members, towards the condition and towards my mother. On encountering these attitudes, especially as a child, I was shocked, frightened, and confused. My opinion on the aetiology of ME/CFS, as espoused below, is now somewhat different. In hindsight, I believe I held on to a biological aetiology as a method of legitimising the symptoms and distress experienced by my mother and acquaintances with ME/CFS. Now I see now that my belief was based on a dichotomous assumption of illness. Symptoms could be either biological, and therefore legitimate, or psychological and therefore fabricated. We can see that my assumption is still adopted by much of society today, particularly in the area of ME/CFS. It is highly present in the 'ME/CFS-fact or fiction' debate<sup>9</sup>. This debate is described eloquently in Moss-Morris and Petrie (2000, chapter four).

I started allowing my mind to consider other explanations when I developed a condition myself, which was evidently affected by both physical and psychological phenomena. I used psychological methods to manage my symptoms and found they afforded me control over what was a frightening and overwhelming experience. I also began working therapeutically with others who had conditions that were influenced by both physical and psychological facets. These were individuals who had difficulties with chronic pain and disordered eating. I experienced first-hand how working with the mind could make things better for the body. Consequently, I was approaching the ME/CFS literature with a more open mind-set. I discovered that there is an undeniable amount of research linking psychological factors and ME/CFS. I believe it to be unethical and unworkable to dismiss this and I now hold

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<sup>9</sup> 'ME/CFS-fact or fiction debate' is not a term the author has seen used as a recognised and established phraseology.

that there are both biological and psychological (and social) influences at work in ME/CFS.

Recognising the distress ME/CFS can cause is still at the forefront of my perspective. I view ME/CFS as a very real experience, which can and does have a significant impact on individuals' identity, self-esteem, confidence, relationships, jobs, hobbies, social groups, and abilities. I believe it is important to highlight this in light of the discourses I have encountered from individuals and groups living with ME/CFS. Specifically, the discourses directed towards psychologists and their perceived agendas. As demonstrated in Moss-Morris and Petrie (2000) and particular Facebook groups I discovered in 2013, psychologists often seem to be considered to be promoting ME/CFS as 'all in the mind'. I am concerned not to be labelled as one of *those* psychologists, described by an internet chat member in Moss-Morris and Petrie as "those omnipotent experts (the Shrinks) [whose] 'thinking' passes for 'research' [and] is certainly revealing, nauseating and passé" (2000, p. 57). Rather, I hope to portray myself as one who validates the condition and the difficulties it can bring. I therefore position myself as below:

I am a trainee psychologist who believes that ME/CFS is a bio-psycho-social experience. I aim to take a validating stance towards the difficulties the condition can bring, and hope not to assume knowledge about individuals' personal experiences.

#### **4.2 The ME/CFS lens**

A supervisor of mine once asked me "if you look through mud-coloured glasses, what are you going to see?" Throughout my analysis her words remained prominent in my mind, as I began to discover that participants often looked through a common lens. For some, ME/CFS had become so overwhelmingly prominent in their lives it was as if they put ME/CFS-coloured glasses on when they woke. Life was

experienced as a management exercise. As Nadia put it – “it is managing, it’s always managing, everything is very controlled” (1204-1206). This focus on management seemed to communicate something deeper. It appeared a manifestation of anxiety. Participants feared both symptoms getting worse and being condemned to a life with ME/CFS forever. The four master themes arising from the analysis seem to share this baseline perspective. In considering the implications of findings for the wider field we therefore need to be mindful of the poignant and overwhelming nature of such a lens.

Many people, including me, would argue that living with ME/CFS can be a challenging endeavour. Literature repeatedly highlights the losses the condition brings. Studies have identified losses of role, relationships, employment, hobbies, and identity (Dickson et al., 2008; Dickson et al., 2007; Asbring, 2001; Moss-Morris & Petrie, 2000), to name a few. As mentioned in the Introduction, there is also the loss of the future self; the person individuals once hoped to be (Dickson et al., 2008; Asbring, 2001). Such losses were peppered throughout the accounts of participants in the current study.

We can see how loss might contribute to developing such a lens when considering cognitive-behavioural theory. Cognitive-behavioural literature argues that we develop certain behaviours with the aim of keeping ourselves emotionally safe. We either act according to rules we have created to protect against our deepest fears coming true, or, we adhere to rules to move us towards what we desperately desire (e.g. Fennell, 2009). Perhaps it is that some people with ME/CFS monitor every aspect and activity in their lives to protect against further loss. Maybe some individuals also hope to move out of the difficult situation they find themselves in, towards a life less affected by their condition. The routine adoption of an ME/CFS lens would therefore serve a self-protective and constructive purpose.

Having ME/CFS also elicits difficulties at a societal level. As mentioned above, literature repeatedly reports that individuals find their illness questioned or delegitimised by their peers and the medical profession (e.g. Brooks et al., 2014; Dickson et al., 2007; Edwards et al., 2007; Moss-Morris & Petrie, 2000). Participants in the current study reported similar experiences, mentioning stigmatising responses from friends and their GP. Patricia vividly sums this up – “the first years of having chronic fatigue were spent with everybody thinking I was loopy anyway, and that I was just indulgent. Oh, yuppie flu and all that” (2232-2238). Individuals in the present study also described feeling their condition was delegitimised by governmental bodies and workplaces.

We can gain insight into the experience of the ME/CFS lens by considering this societal prejudice alongside developmental and evolutionary theories. In evolutionary terms, the need to remain in the tribe is of pivotal importance because it vastly increases our chances of survival. Anxiety around rejection is therefore adaptive and we are designed to feel this keenly (Harris, 2009). Similarly, literature looking at early life attachments might argue that we are born with a fear of abandonment, which repeats throughout our adult life. We need to be hyperaware of whether our primary caregiver is there to feed us and keep us warm and safe (e.g. Ainsworth, Blehar, Waters & Wall, 1978). Protecting against rejection appears inbuilt, and again we can understand why seeing through the lens of illness becomes so important.

I would argue that the frequent adoption of the ME/CFS lens presents implications for the MBIs we conduct as psychologists. We might expect that anxiety around MBIs will be high. Although IPA studies cannot be generalised, the data gathered in the present study gives insight into particular facets about which individuals might be anxious. An overwhelming source of anxiety for the present participants was that of activity. As we saw, particularly in Harriet and Irv’s accounts, individuals may be

nervous about the overall activity required from sessions and the likely impact of this on symptoms. As illustrated in Lucy's account, participants might be worried about specific practices affecting symptoms. Consistent with Irv's data, people may be concerned about the impact of travel on symptoms. As also highlighted by Irv, participants may worry about being forced into activities by facilitators they feel unable to assert themselves to.

This anxiety around activity opens a debate with two strong opposing arguments. On the one hand, it could be argued that the best path for facilitators to take would be to lessen participants' anxiety by minimising the activity involved in MBIs and communicating the steps taken to do so to individuals. There are two overarching reasons why this might be the best route. The first centres on ethics. Lessening anxiety and activity is arguably the most moral decision. We know that activity typically heightens symptoms for people with ME/CFS (e.g. Morris & Maes, 2013; Arroll & Senior, 2008; Fukuda et al., 1994). Indeed, this was reported in the current study and was particularly evident for Harriet, for whom a two-hour mindfulness session left a "residue" for days afterwards (line 1778). Reducing activity is therefore an obvious ethical step, as we wish to cause as little harm to our clients as possible. As well as physical harm (heightened symptoms), we have an ethical responsibility to reduce psychological harm and thus the distress that worrying about interventions might bring. Moreover, reducing psychological distress is likely to further reduce physical harm since research tells us that, as well as activity, anxiety and emotional upset can heighten symptoms too (e.g. Morris & Maes, 2013; Wearden & Emsley, 2013; Deary & Chalder, 2010; Chalder, Neeleman, Reme, Power & Wessely, 2010). Indeed, Patricia described emotional stress like "opening a tap [] all [her] energy goes" (1218-1220). Again, reducing activity and the emotional stress this causes is an ethical step, working to maintain participants' quality of life during the period of the course.

The second reason centres on attendance. As described in the Analysis section, Lucy said, “I signed up for courses with them before and I ended up cancelling cos I just thought I can’t make it” (304-307). Lucy was not the only participant to demonstrate avoidance with the aim of managing symptoms. Avoiding activity to reduce symptom exacerbation has also been reported frequently in the literature. For example, pacing, the spreading out of activity and living within one’s known limitations, was reported to be a successful management technique by 1,522 of 2,137 respondents (71.2%) to the MEA’s (2010) survey. Taking practical steps to reduce the activity involved in MBIs may be more likely to mean that individuals will attend and engage with interventions that have the possibility to help them.

On the other side of the debate, it could be argued that the best path for facilitators to take would be to *not* minimise activity. Again, there are two overarching reasons why this might be the best route. The first centres on quality of life and can be explained through an anecdote from my clinical practice. As noted earlier, I have previously worked in an eating difficulties service. Here each client was expected to write down, item for item, each portion of food or drink they consumed on a daily basis. For some this appeared a useful exercise, whereby the mapping of their achievements afforded hope and inspired further progress. For others, such journaling appeared to maintain a focus on food detrimental to progress. Narrowing their attention to food detracted from them considering and engaging with dreams, hobbies, and relationships and those other intricacies which make life worth living. As therapists, we fed into this process, encouraging clients to reduce their life down to food and its control. Facilitators focussing on symptom reduction could be seen as a parallel process. Like me and the other therapists who encouraged a narrowed focus on food, in focussing on activity MBI facilitators might contribute to ‘tunnel vision’, indirectly encouraging clients to funnel their life down to ME/CFS symptoms

and controlling these. It could be argued that in this way MBI facilitators contribute to reducing their clients' quality of life.

The second reason centres on what is reported by research to elicit long-term improvement in ME/CFS symptoms. In contrast to the common and arguably dominant ideology, literature suggests that encouraging individuals to reduce activity is actually *counterproductive* to long-term improvement (see Moss-Morris & Petrie, 2000). Instead, research has found that treatment protocols which focus on increasing activity and reducing fear around this can lead to long-term improvement in symptoms (White et al., 2011).

Having weighed up each side of the debate I personally support the former arguments and believe that reducing activity is the best step to take in this context. It is our duty as therapists to minimise harm. Also, we cannot help anyone through group-based MBIs without them attending. Furthermore, those elements found by White et al. (2011) to be useful - reducing avoidance and fear - are typically addressed in MBI course material anyway. Interventions tend to increase awareness of individual patterns (i.e. what makes one scared and when this occurs), as well as how to effectively manage thoughts and their impact. From a workability stance I would argue that the pros of reducing activity for the duration of the course outweigh the cons.

Practical steps facilitators could take to reduce anxiety, as collated from the current research, are as follows:

- Present oneself as open and approachable
- Adhere to time limits
- Communicate understanding of the condition
- Provide a room at an adequate temperature

- Provide blankets if cold
- Encourage individuals to call in advance regarding special requirements (e.g. dietary needs)
- Provide travel to and from sessions
- Wear clothes likely to denote gentle activity to clients
- Ensure a quiet rest space is provided before and after the course for those who might need it (e.g. before the journey home)
- Send information about the intervention well in advance – including information about the steps that will be taken to minimise unnecessary activity
- Give participants the option to sit or lie during practices
- Mix activities (e.g. practice then discussion then break)

#### ***4.3 Further considerations of stigma***

As mentioned earlier, there is much evidence to suggest that psychological factors play a part in the aetiology of ME/CFS (Wearden & Emsley, 2013; White et al., 2011; Deary & Chalder, 2010; Chalder, Neeleman, Reme, Power & Wessely, 2010; Moss-Morris & Petrie, 2000). However, individuals have been known to react angrily to research and researchers who suggest a psychological aetiology. It is thought this is because patients, doctors, and the public believe that promoting a psychological aetiology assumes symptoms are imaginary (Moss-Morris & Petrie, 2000).

This assumption is well known. I would argue that we can expect people who attend MBIs to come with at least some experience of being stigmatised against or knowledge of the debate. Indeed, participants in the current study reported worrying about their peers' and facilitators' responses to their illness. This anxiety appeared

to arise from an awareness of prejudice and all participants spoke at some point about the controversy surrounding the condition. Interestingly, a discourse around mindfulness assuming ME/CFS is 'all in the mind' was absent from participants' accounts. This might be with the exception of Harriet who questioned whether the mindful movement exercise held a hidden fitness agenda. But even for Harriet the mechanisms of change in mindfulness were not assumed to focus on psychology, or to belittle the condition. Here I consider reports of focussing on the present moment, switching foci of attention, interrupting thought patterns, and acceptance of sensations. Despite all of these mechanisms being related to the mind, none were judged to assume ME/CFS is a fabricated condition.

Perhaps this lack of judgement can be attributed to three factors. How the MBIs were marketed, the communications given by facilitators, and participants experiencing for themselves an interaction between psychology and symptoms. First, participants appeared to describe their MBIs as being focussed on management rather than treatment. No participants mentioned MBIs or mindfulness alongside the word 'psychological' or any similar derivative. Perhaps mindfulness was not advertised to fall into the realm of the psychologist and was, therefore, not judged in this capacity by participants. This may suggest that avoiding psychological positioning in advertising could be important in developing an openness to mindfulness and its potential.

Second, facilitators were mostly considered to be sensitive and respectful to participants and their conditions. Interestingly, the psychology and ME/CFS research that I have seen heavily critiqued by individuals and patient organisations appears to be rather clinical. It could be argued that this clear and academic narrative is necessary. The purpose of the research article is to present findings, bearing in mind a relatively limited word space. If individuals were to read such research when anxious about being stigmatised against, the clear cold narrative

could be construed as invalidating. Patient experience could be seen as dismissed or delegitimised. Koerner (2012) explains that when we feel invalidated we frequently have a strong emotional reaction. She says that when we are in this state we are unlikely to process any new information and instead hold on tightly to our existing beliefs. Consequently, if individuals feel invalidated by what they perceive to be cold and clinical research articles, they are less likely to consider the research on its own merits. We also see that sensitive facilitators who validate individuals' illnesses are important in helping people to keep an open mind about mindfulness and MBIs.

Third, participants described experiencing for themselves an interaction between psychology and symptoms, even though this was not necessarily termed as such. For example, Lucy described watching the pain her course peer was experiencing subside whilst practising mindfulness. We saw that she described this as the "penny dropping", a realisation that mindfulness could give her some control over her symptoms (line 787). Beforehand, Lucy had described being sceptical that mindfulness could help her. It could be that experiencing improvements first-hand makes individuals more likely to see potential in psychological interventions, such as mindfulness, for improving ME/CFS.

We can see that the stigma discourse and awareness of this is likely to affect how open-minded people are to MBIs and other psychological interventions. If we believe ME/CFS to be solely a biological illness we see it as something amenable only to biological intervention, for example medication. In this instance, mindfulness becomes pointless. However, if we believe ME/CFS to be influenced by psychological factors as well, we see it as amenable to psychological intervention too. Mindfulness in this instance therefore has potential. This can be seen in the accounts of Patricia and Lucy. Patricia appeared to approach ME/CFS and mindfulness from the standpoint that the mind and body are inextricably linked. She

showed awareness of the discourses around psychological explanations and delegitimation, but positioned herself outside them. For example, Patricia said, “I think that stress and physical conditions are very strongly related” (75-78), then later added, “I think I might still be desperate without [mindfulness] [] I might be in that group of people who erm is really angry when anyone suggests that there’s a psychological element to chronic fatigue, because they think they’re being told that they’re mentally ill” (707-715). Patricia also showed an enormous amount of hope. She persevered with mindfulness despite years of being confused about how to practice it and not seeing benefits. It seems that Patricia’s belief in mindfulness’ potential led to her continued engagement with it. Imagine if Lucy, who was highly sceptical as to the potential of mindfulness, had not seen her peer experience such change. It is not unreasonable to assume that Lucy’s experience and overall outcome would have been much less positive in this case.

#### ***4.4 The therapeutic relationship***

##### **4.4.1 Between group members**

For many years practitioners have known that groups have substantial therapeutic potential. As explained by Kivlighan, Miles and Paquin (2010), Yalom and colleagues were among the first to assess therapeutic factors in the context of the group. Yalom, Tinklenberg and Gilula (1968, as cited in Kivlighan et al., 2010) produced a framework of 12 components thought to capture fundamental change processes in group therapy across treatment settings, populations, problems, and therapeutic styles. These 12 components are described in Kivlighan et al. (2010) and include the giving and receiving of support, feeling connected to others, and being instilled with hope.

As we might expect, experiences of peer relationships appear commonly espoused in qualitative studies investigating MBIs. As described in the Introduction, peers are

noted to influence engagement, how participants feel during interventions, and how individuals feel about themselves - their 'self-relationships' (e.g. Poppe et al., 2013; Malpass et al., 2011). Irving et al. (2014) explained that many of their participants spoke about the group structure facilitating their persistence with mindfulness. Individuals spoke about being in the MBI room as almost forcing one to practice. This phenomenon appeared present in the current study too. Richard talked about his sense of comradeship and obligation to his group encouraging him to engage with practice. Caroline spoke similarly. She explained that although she found her facilitator's guidance poor, she believed there was worth in attending the group because she felt encouraged to practice whilst there. Like participants in the current study, individuals in Irving et al. (2014) described being forced into practice as a positive experience. Peer relationships therefore appear therapeutic for some, due to their influence on engagement and perseverance with mindfulness practice.

Irving et al. (2014) spoke about how feeling supported and experiencing a sense of mutuality with course peers seemed central to the facilitative nature of participants' MBI group. In particular, attending the MBI was perceived by individuals as an opportunity to learn that others struggled and suffered with the same things. Similar findings were reported in Malpass et al. (2011) who conducted a meta-synthesis of qualitative papers. They reported that participants across many studies spoke about shared experience, in particular learning that others have similar problems. It was reported that this led to a sense of being normal and less isolated and was important for accepting one's illness or difficulty. Such experiences appear reflected in the present study too. For Harriet, perceiving others as similar to her and understanding her led to a sense of relief. She also described acts of being supported by her group and it seemed she felt heard and considered by them as a result. Irv reported feeling understood by his peers and said this cultivated a sense of being under less pressure. He also recounted experiencing a reduction in guilt

when he realised others felt guilty because of their illnesses too. Caroline spoke about learning that others experienced the same issues as her, which led to a reduction in her feelings of isolation and a sense of belonging. Again, Nadia said that finding commonality between her and other group members led to a sense of being normal.

I wonder whether perceiving oneself as similar to others and gaining support from group members were so important to the current participants due to the wider discourses around ME/CFS. It has been noted that ME/CFS is an illness frequently stigmatised against. As postulated earlier, such stigma may create an anxiety around being judged or misunderstood by others. Perhaps feeling accepted, supported, and similar to others was so important because it gave participants a sense of safety in an unsafe world.

An interesting reading of the data emerges if we consider findings from Brooks et al. (2014). In their IPA study, Brooks et al. (2014) reported that significant others such as partners (and in one case the proprietor of a health shop) played an important role in individuals' experiences. This was in the context of healthcare professionals being unable to provide a definitive diagnosis or curative treatment. Finding themselves in a situation where they were unable to obtain answers from the sources they would usually access, individuals sought information and support from those close to them (Brooks et al., 2014). Similarly, participants in Edwards et al. (2007) reported gaining information by speaking to other individuals with the condition, through reading, and via the internet. As in Brooks et al. (2014), the seeking of such information was talked about in the context of dissatisfactory healthcare input. Participants in the current study espoused similar views. For example, Caroline referred to a process of giving and receiving information, "somebody has a problem and you think, 'Well I tried it this way, try that', and then they say the same to you, so you're constantly sharing" (698-701). Caroline

explained that this sharing was “beneficial” because peers were “helping each other” (line 697 / 696-697). Therefore, as well as finding a relief from stigma and a sense of belonging, the group also appears potentially important for the giving and receiving of healthcare information. Perhaps, as espoused in Caroline’s account and the participants in Edwards et al. (2007), this can give a sense of gaining new information and of understanding one’s situation better.

I would argue that learning about the importance of peer relationships has particular implications for practitioners intending to conduct group-based MBIs with individuals living with ME/CFS. It could be suggested that the group may be just as therapeutic as the mindfulness skills themselves. Indeed, participants in other studies have noted as much. Two participants in Smith, Fergal, Jones, Holttum and Griffiths (2014) did not report much change from the MBI sessions, but did talk about valuing the group process, one saying it was “nice to know that somebody else was suffering just like you” (p. 4). In the current study, Caroline very specifically stated that the group process was more valuable to her than the sessions. She said “I got more out of the group as we were talking at break erm than I did with the session” (703-706). A similar essence shone through Irv’s account. He reported finding the group very therapeutic, but only finding worth in the techniques a few months after the sessions had finished. Irv said about his first session, “What I actually got from it was the fact that I’d met some people [] I’m talking to people who understand and they’re listening and I’m listening to them” (786-792). Irv spoke about this interaction meaning he took something away that was “more readily available” (789-790). Interestingly this sense of accessibility (or non-accessibility) appeared echoed in Smith et al. (2014). Here, the aforementioned participant described the mindfulness practices as very difficult to engage with and complete.

Therefore, perhaps practitioners need to provide a space where peer relationships can prosper. The wider literature supports this assertion and authors such as Yalom

and Leszcz (2005) have provided guidelines to this end. Richard gave insight in his interview into how he believed his facilitators helped build successful group dynamics. This appears consistent with the advice given in the aforementioned guidelines as he explained that his facilitators had methods of being warm and respectful to participants, yet ensuring conversation was moving so that certain individuals did not dominate the interaction.

Yalom and Leszcz's (2005) guidelines also consider the selection of clients and the composition of therapy groups. They suggest that diagnosis is less important in predicting group behaviour than are attachment and personality. Despite this, since feeling that one is not alone or unique in their problems and suffering is thought so important for therapeutic change (e.g. Yalom et al., 1968, as cited in Kivlighan et al., 2010), perhaps it would be helpful to bring together groups of individuals likely to be able to resonate with each other. This might mean others with ME/CFS, or those experiencing conditions characterised by similar symptoms such as fibromyalgia or chronic pain. Perhaps it may also be helpful to dedicate an amount of session time to group communication, during which individuals could speak to one another and discuss their experiences. For example, participants in the current study spoke about spending breaks catching up with peers. I wonder whether splitting the larger cohort into smaller groups for certain activities might also achieve the same goal. Here participants may have more opportunity to communicate. They could also feel more comfortable talking without the gaze of the facilitator, who may well be perceived as wanting individuals to stay focussed on the task in hand.

#### **4.4.2 Between facilitator and group**

The quality of the relationship between therapist and client has long been understood as influential to client progress (e.g. Lambert & Simon, 2010). Largely it is thought to be therapist empathy and a sense of feeling understood by therapists which is particularly influential to the outcome (e.g. Miller, Taylor & West; Lafferty,

Beutler & Crago, as cited in Lambert & Simon, 2010). We can see that such findings are supported by the accounts related in the current study. For example, Lucy appeared to feel understood by her facilitator and perceived her as aware of and sensitive to her needs. In contrast, Harriet reported a tangible sense of distance from her facilitator. This was strikingly evident when Harriet said, “You think she’s not struggling in a rented flat and she can’t unpack” (298-300). Lucy and Harriet described vastly different outcomes. Lucy found mindfulness useful to manage her mood and symptoms, and reported increased quality of life. On the other hand, Harriet described mindfulness as mostly unhelpful and making no long-term difference to her health or life satisfaction. It could be argued that the ability of the facilitator to empathise with clients and to communicate this understanding is crucial for successful MBI outcomes.

Literature suggests that individuals consider the facilitator to be an important influence on the atmosphere of MBI groups. For example, Hopkins and Kuyken (2012) reported that participants in their study regarded the facilitator as contributing to the generation of a compassionate atmosphere. This caring and empathic space was valued by those encountering it. In the current study, participants also considered the facilitator to contribute to a sensitive, comfortable, and friendly atmosphere. Nadia spoke about observing behaviours in her facilitator which she felt communicated care and compassion towards clients. In particular, Nadia noted the facilitator putting the mats out for individuals in the group and providing drinks and biscuits. Nadia sums up her experience by saying, “It could have been a very different course. It could have been run by somebody who doesn’t really care, and it’s kind of those motherly homely touches, you know, which just make it better, a nicer environment” (750-758). Irv also reported observing his facilitators’ behaviours and generating from them a sense of being accepted and cared about. He noted facilitators closing the blinds in the room before the course

so that it was not too hot for clients. A real sense of being thought about shines through his account, “They’d put the thought into [] not leaving the blinds open cos it was very bright, so they’d slightly closed those, which was considerate” (639-644). Similarly, Lucy spoke about her facilitator asking her beforehand about the mindful eating practice and amending the exercise based on Lucy’s dietary needs. Lucy described her facilitator’s actions as turning her negative feelings into positive ones, “The negative became a positive there because [] she amended it” (1345-1348). I believe this holds implications for best practice. In particular, it seems that being proactive and showing thoughtfulness and consideration in action is likely to build stronger therapeutic relationships.

Literature suggests that individuals tend to compare themselves to their peers and facilitators during MBIs. Less positive accounts of facilitators have centred on ‘upward social comparisons’ (e.g. Hopkins & Kuyken, 2012), whereby facilitators are seen as ‘doing better’ with mindfulness than clients are. Participants described finding it difficult to hear of others’ positive experiences when they were not experiencing similar (Hopkins & Kuyken, 2012). This was reported to increase feelings of isolation and, for one individual, led to envious and hostile feelings toward his teacher. This participant, Mark, spoke about the person guiding his class being “so devoted to their own practice” and described how this came across as “a bit smug” (p. 145). Such social comparisons appeared common in the present study. Like Mark, Harriet described comparing her experience of mindfulness to that of her facilitators – “it seems to have changed their lives [] but it hasn’t worked like that for me” (415-423). Similar to Mark, Harriet seemed to communicate that she thought her facilitator’s commitment to mindfulness was a little over the top. She said, “She told us about relaxation she did at home [] she’d got a special spot for it and you think, ‘My goodness’” (237-242). Harriet seemed to turn her frustration in

on herself, engaging in self-blaming and criticising behaviour for mindfulness not having a more beneficial effect.

The above consideration of facilitators' passion seems interesting when we consider other participants' reports of their teacher's zest for mindfulness. Such enthusiasm was considered in a much more positive light by other participants. For example, Lucy described being inspired when observing her facilitator's keenness. Caroline gave an impassioned account of desiring a facilitator who was enthusiastic and committed to mindfulness. Perhaps there is an underlying issue here of accessibility. When we compare the accounts of participants, we see that passion was considered positive if participants felt able to replicate such engagement, or if they were experiencing or believed they could experience similar benefits. Passion appeared to be considered less positive when participants felt unable to replicate practice as shown, or experience such utility for themselves. I believe this connects to the issue of guidance.

Analysis suggested that guidance was an important gatekeeper to connecting with and experiencing benefit from mindfulness. As espoused in Patricia's account, guidance was needed which "made that shift" from instruction to action (line 1589). To provide such guidance, I believe facilitators need to practice mindfulness themselves and thus be able to explain what the process is like for them. My opinion seems supported by Caroline's account as she explained that clients in the MBI she attended appeared lost because the facilitator "couldn't answer" questions about how to conduct mindfulness practice (line 246). Similarly, van Aalderen et al. (2014) found that nine out of 10 clients in their study considered it crucial for facilitators to meditate themselves. Facilitators were hoped to "know mindfulness meditation, from their own experience" (p. 172). Quotes from participants suggested that clients considered facilitators' knowledge of the process important. Facilitators were expected to "know what is going on when meditating" (p. 172). A similar

opinion appeared espoused by facilitators in van Aalderen et al. (2014). They said that teachers needed to be able to give examples from their own life so clients could understand how to integrate mindfulness into their lives too. It seems that ensuring facilitators are experienced in using mindfulness to manage their own difficulties is an important step for future MBI organisers.

#### ***4.5 Acceptance and coping***

We have seen that for some of the current participants, acceptance was an important factor in their coping experience. Acceptance was understood to be associated with mindfulness, both in mindfulness philosophy and in the practice of mindfulness. Acceptance seemed to mean different things to different participants and appeared to result in differing outcomes. Daniel talked about acceptance of symptoms and their limitations. He spoke about this acceptance meaning he could focus on the enjoyable aspects of his present experience. Lucy talked about acceptance of emotions, meaning she became able to openly consider what her mental state might be. Both Patricia and Nadia talked about accepting themselves and, like Daniel, the limitations placed upon them by their conditions. For Patricia and Lucy, acceptance seemed to mean that they were able to break existing patterns of thinking. For Lucy this pattern was pretending that things were okay and for Patricia it was judging herself as not good enough. Nadia described practising mindfulness as akin to practising acceptance.

We can see that there are some similarities between the findings in the current study and the wider literature. As we saw in the Introduction section, similar to the current study, Coffey et al. (2010) also highlighted acceptance as a central facet of mindfulness. They too found that acceptance meant individuals became clearer and more accepting of their emotions. As in the current study, this acceptance was considered by Coffey et al. (2010) to lead to an improvement in mental health. Interestingly, Coffey et al. (2010) also reported that they found acceptance to

impact upon wellbeing to a greater extent than present-centred attention. It could be argued that this finding is upheld in the present study. The current participants seemed to speak more often and more passionately about acceptance and its effects than they did about attention.

As highlighted in the introduction, quantitative studies including Poppe et al. (2013), Brooks et al. (2011), and Van Damme et al. (2006) have explored the role of acceptance in ME/CFS. Brooks et al. (2011) found that CBT increased participants' acceptance, meaning it reduced individuals' need to attempt to avoid or control fatigue. This was a meaningful finding since the study also found that acceptance was linked to fatigue levels, physical functioning, and work and social adjustment. It could be argued that such findings are reflected in Daniel's account. He spoke about accepting symptoms for what they were on a day to day basis and working around these. It seemed this attitude allowed Daniel a certain sense of adjustment and a subsequent appreciation for the life he was able to lead. As a consequence of their findings, Brooks et al. (2011) suggested that research into ACT might be warranted. As we saw in the Introduction section, ACT is an MBI developed from the CBT School and which traditionally focuses on acceptance.

I would agree with this suggestion and believe that findings from Poppe et al. (2013) further support this. Poppe et al. (2013) considered acceptance in a more holistic form, i.e. whether individuals had learned to live with their illness and the limitations it brought. Interestingly, Poppe et al. (2013) found that acceptance was related to increased emotional stability and less psychological distress, *beyond the effects of fatigue severity*. In other words, the severity of individuals' symptoms was not always important. Acceptance could have significant effects on participants' wellbeing regardless of this. Moreover, Poppe et al. (2013) suggest that even with CBT treatment, recovery rates for ME/CFS are still low, with the majority of individuals continuing to live with the condition for significant periods of time. Other

research supports this finding (e.g. Cairns & Hotopf, 2005). Might it be better for psychologists to provide treatment that not only works on improving symptoms but also helps individuals build a rich and meaningful life with ME/CFS? Perhaps ACT, with its focus on improving quality of life rather than improving symptoms per se is particularly equipped for the long-term limitations that many with ME/CFS are likely to face. Van Damme et al. (2006) appear to agree with this, concluding that promoting acceptance in patients with ME/CFS may often be more beneficial than trying to control largely uncontrollable symptoms.

Findings from the current study may be useful here. As explained in the Introduction, one of the gifts of qualitative research is that it allows us to gather spontaneous data. Thus, we are able to obtain a nuanced understanding of processes which the more restrictive quantitative methods do not allow. The current study has shed light on elements which might help increase acceptance or assist the acceptance process for individuals with ME/CFS. In particular, participants spoke about mindfulness as increasing or facilitating acceptance of their conditions and situations. This included the philosophies of mindfulness and the actual practice of it. Realising that other facets of life can be important or enjoyable despite the condition also appeared to help cultivate acceptance. This appeared particularly true of relationships, with acceptance of one's situation growing as one gained connection and friendship with others. Sharing troubles and struggles seemed to give individuals a sense of validation, and individuals appeared to begin to accept their experiences when they realised other people shared the same emotions.

The theme of acceptance also appears prevalent in the qualitative literature focussing on ME/CFS. Again, acceptance is thought to be an important part of the coping process. It is considered to refer to a tolerance and compassion towards one's situation and emotions. In their study exploring identity crisis, loss, and adjustment, Dickson et al. (2008) explain that "acceptance was a fundamental

component in shaping participants' adjustment to living with CFS" (p. 467). Findings from the current study appear similar to this, as acceptance was reported by participants to influence adjustment to life with ME/CFS.

Dickson et al. (2008) reported that participants understood time to be the influencing factor on adjustment to life with ME/CFS. Interestingly, the current participants spoke about mindfulness and their MBIs as being the catalyst for this adjustment process. Although mindfulness rather than time was the catalyst, acceptance appeared reported to work in similar ways in both studies. A link between acceptance and identity as highlighted in Dickson et al. (2008) was also evident in the current study. Both sets of participants spoke about a shift towards accepting one's illness identity rather than grieving the loss of the selves they had once been, or once expected to be. Similarly, both participant groups talked about the acceptance of illness identity being linked to mood. For Nadia, accepting herself with ME/CFS had not happened. As we saw earlier, she spoke of herself having depressive periods because she had not yet "come to terms with the fact that [she has] effectively a debilitating illness" (96-98). Daniel and Patricia appeared much further on with accepting their illness identity. As Patricia said, "The only thing one can do is to understand how to live your life to your own best advantage" (1048-1052).

I believe these findings hold implications for the use of MBIs. In particular, it seems that, similarly to the quantitative literature, the qualitative literature also advocates ACT as a helpful approach for individuals with ME/CFS. Dickson et al. (2008) explained that adjustment to life with ME/CFS meant the integration of the once desired or anticipated self into the current 'ill' self. Findings from the current study suggest that mindfulness can facilitate this process. This in itself would indicate ACT as a potential therapy. Additionally, Dickson et al. (2008) explain that acceptance facilitated this integration of selves because individuals started to take

actions consistent with the people they wanted to be.<sup>10</sup> What we can take from this is the hypothesis that ACT, with its focus on encouraging values-congruent action within realistic limitations, might be a particularly helpful approach for individuals having difficulty accepting their ME/CFS identity.

#### ***4.6 Working with scepticism, cynicism and doubt***

Accounts of scepticism, cynicism and doubt appear numerous within the mindfulness literature. In particular, authors have noted that participants entered their MBIs with a level of initial hesitation (e.g. Smith et al., 2014; Hopkins & Kuyken, 2012; Langdon et al., 2011). As in the current study, reservations appeared directed toward religious encounters (less common) and questions about whether mindfulness ‘works’ (more common).

In the analysis section we saw that initially Daniel wondered whether his facilitators would try to convert him to Buddhism. Daniel explained that his mind was put to rest when he attended the course and found this was not the case. Religion no longer acted as a barrier for him. In contrast, we saw that religion did act as a barrier for Harriet. She perceived her facilitator as “bringing a sort of faith thing into it” (2281-2282) which resulted in Harriet being distracted from the practice. Participants in Morgan, Simpson and Smith (2014) spoke about religion. Similar to Daniel, it seemed that some of their participants experienced initial scepticism related to whether meditation would clash with existing beliefs. Again, they reported positive experiences when this was found not to be the case. It seems Harriet’s account shows us what might happen when mindfulness is found to clash with existing beliefs - the disengagement from practice.

Literature appears to show both consistencies and divergences when considering reservations about whether mindfulness ‘worked’. What appeared to be consistent

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<sup>10</sup> The process of this is explained in more depth in Dickson et al. (2008).

was the wondering about whether mindfulness could help the individual and move them on to a better place. As we might expect, what that better place was imagined to be appeared to differ between studies and individuals. Some participants in Sears, Kraus, Carlough and Treat (2011) espoused expectations about instant transformation and mindfulness practice making one happy. Participants in Smith et al. (2014) appeared to be attending their group to learn to manage their depression better and increase mood. These findings appear relatively consistent with data from the current study. Many participants talked about pre-course expectations that often seemed directed towards whether mindfulness could make any difference to their conditions. As we have seen, such hopes seemed to lead to a state of vigilance. Individuals continually judged the utility of the material, espousing the belief that the only point in attending the course was to improve symptoms.

These findings regarding scepticism and MBIs appear to hold implications for conducting future interventions. As we saw from Daniel and Harriet's accounts, enforcement of religious beliefs was met with resistance and, in Harriet's case, disengagement. On the surface, it could be argued that best practice would be to keep religion completely separate from interventions. However, there appears to be a substantial body of research which suggests that the outcome of psychotherapy for religious individuals can be enhanced by incorporating religious elements into treatment (see Hefti, 2011). Indeed, Nadia's account appears consistent with this. Nadia talked about liking mindfulness especially because it fitted well with her religious beliefs. For Nadia, mindfulness was a way of fulfilling her spiritual potential. She said, "I'm quite a spiritual person so [] coming back to the truth and how you really are and being honest about that erm resonates with me" (333-338). She also said, "I feel like I have [] a true destiny, or I want to be the best I can be, and I feel that in order to do that it involves a lot of self-development, self-analysis, and meditation" (345-352). Nadia's account appears consistent with findings from

Morgan et al. (2014) in which participants spoke positively about mindfulness training integrating well with their religious or spiritual beliefs. Rather than ignoring religion in MBIs, perhaps it may be more helpful if it was incorporated into the process when necessary. For example, facilitators could spend time with religious or spiritual individuals discussing how mindfulness could be integrated within their own practices and belief systems.

It may also be important for facilitators to actively manage participants' expectations from the beginning of interventions. In particular, participants might profit from learning about how mindfulness has been known to benefit individuals in areas other than symptom reduction. In this way, participants may look past whether mindfulness 'works' and gain more from their MBI experience. Indeed, significant gains separate from symptom reduction were reported by individuals in the current study. Lucy and Patricia appeared to experience a similar phenomenon – the ability to connect to previously inaccessible thought patterns. As mentioned earlier, Lucy reported almost a reversal of denial. She was able to move from a more narrowed lens to an open and non-critical consideration of her mental state. Notably, Lucy was able to allow herself to acknowledge that sometimes she did find things hard emotionally. Patricia spoke about a particular practice – the Recognise Allow Investigate Non-identify (RAIN) practice – allowing her to explore previously "hidden" material kept "behind lock and key" in her mind (line 1751 / line 1752). Patricia explained that, not only was she able to access this material, she was also able to engage in a process of resolving it. This meant the issues were "losing their power" (2123-2124).

Patricia recounted other benefits of mindfulness too. It seemed that practice had given Patricia a space of reflection, through which she had created a psychological formulation as one might in therapy. She said, "I have learned so much about myself and [] how everything fits together" (187-190). As often occurs in therapy,

Patricia reported that this knowledge had allowed her to change her interpersonal patterns and become altogether a more relaxed and contented individual. As we saw earlier, Patricia also spoke about mindfulness philosophy leading to her accepting herself as she is. This appeared significant for Patricia since she reported a long history of self-criticism and feelings of not being good enough. Daniel talked about benefits from a different angle. As explained earlier, Daniel found that both learning about and practising mindfulness allowed him to make the most of life. He espoused a very grateful stance, explaining that mindfulness permitted him to become aware of and appreciate the good things in his life. Reporting of such gains to participants at the beginning of the MBI process may help individuals perceive benefits in a more holistic manner. Thus, participants may be assisted to access more widespread benefits.

#### ***4.7 Critique and limitations of the current study***

Overall, the current research methodology achieved what I hoped it would. It allowed me to illuminate the phenomenon of engaging in MBIs whilst living with ME/CFS. As anticipated, findings have identified helpful and unhelpful aspects of the interventions, and given information about why these facets were found to be so. As hoped, the findings seem able to contribute to the development of future interventions as well as add to an evidence-base regarding ME/CFS and MBIs. As with all research the process has not been faultless. The following section discusses how the current study could be critiqued. Here, issues of clarity, sampling, and demographic information are discussed. Some of these are explored further when considering implications and options for future research.

One of the main critiques of the current study is the mismatch between the research question and the sampling process. Initially I hoped to consider a range of MBIs with the commonality which tied them together being that the interventions were all founded on mindfulness in some way. However, my most fruitful recruitment

method was a round robin email sent by an organisation providing solely group-based interventions. As discussed in the Methodology section, I believe this worked out for the best as this initial aim may have generated a data set too diverse for deep and meaningful analysis. Instead, I was able to gain insight into common phenomena from a variety of angles. I decided not to change the term 'mindfulness-based interventions' to another, such as 'mindfulness courses', as I felt this would create inconsistency in my write-up. Recruitment materials and the information sheet would have referred to 'mindfulness-based interventions', whereas the write-up would have referred to a different term. I thought this might cause confusion, especially for my participants who expressed keen interest in reading the final product. Moreover, the term 'mindfulness-based interventions' still encompasses the courses participants spoke about and is therefore technically accurate.

Sampling in the current study is worthy of discussion too. The first point to consider links with the above discussion of clear communication. As mentioned in the Methodology section, presenting individual profiles would have compromised confidentiality due to volunteers approaching me after my recruitment talk in full view of the group. This is unfortunate, as I find individual profiles help connect readers with the accounts they are presented with. I believe readers are more able to empathise if they have a feel for a person and thus the participant's lived experience becomes more alive. Being able to provide individual profiles would therefore have been more consistent with the aim of IPA and of the current study - to illuminate and communicate the experiences of participants. In hindsight, I would have provided contact details and asked interested individuals to contact me after the talk rather than at the venue.

The second point to consider is the exclusion of individuals who had experienced MBI for less than six weeks. As explained in the Methodology section, this was considered a positive and necessary step to ensure that participants had enough

experience from which to provide detailed data about their interventions. It also meant that findings could be compared against a variety of other studies which have reported data from individuals with a similar level of attendance. However, requiring attendance for six weeks possibly means participants were interviewed who were all relatively committed to their MBIs. Even Harriet, who remained sceptical about the utility of mindfulness, attended all sessions and completed all the homework. Scepticism, cynicism, doubt, and the barriers these erected towards mindfulness and MBIs were found important facets of individuals' experiences in the current study. It could be that I would have learned more about negative experiences of MBIs and barriers to engagement if I had interviewed individuals who attended fewer sessions.

The third point to consider regarding sampling is the growing body of literature critiquing the use of the Fukuda et al. (1994) diagnostic criteria. Researchers such as Brown, Jason, Evans and Flores (2013), Jason et al. (2012), Sullivan, Pedersen, Jacks and Evengard (2005), and Jason, Torres-Harding, Jurgens and Helgersen (2004) argue that what the literature commonly refers to as ME/CFS may not be one specific group. Rather 'ME/CFS' may be seen as an umbrella term which encapsulates different symptom clusters, aetiologies, and severities. It may be the case that the current sample consisted of individuals who could be categorised into different subsets. If this is the case, it might mean it is questionable to assume that the current sample is representative of one overarching condition. Perhaps instead, different participants are representative of different subsets. In light of this, it may be suggested that we cannot assume the current data is comparable against other research into ME/CFS. On the other hand, it could be argued that the potential of samples to represent different 'conditions' or 'categories' is only a problem if researchers are looking to generalise findings to wider populations. Here we would hope for the sample to be representative of a larger populace. We want to be

confident that a certain percentage (usually 95-99%) of individuals would respond the same as those in our research. Obviously as IPA is conducted in small sample sizes, in this case eight participants, we are not looking to generalise from findings. Additionally, IPA prioritises experience, not correlates of diagnosis, at the forefront of the investigation. We are not looking to compare individuals based on their diagnoses. Rather, we are seeking to compare and elucidate experiences. Thus, the question of whether the current sample was made up of different subsets holds less importance than we might initially imagine.

The fourth point to consider regarding sampling refers to the motivations of those who volunteered for the study. Rozmovits and Zeibland (2004) espoused in their research that it was inevitable that participants who took part in their interviews differed in a particular way from other similar individuals. Rozmovits and Zeibland (2004) noted that their participants were willing to tell the story of their illness to benefit others. Nelson (2010) echoes a similar sentiment in her research, noting that individuals may be drawn to volunteer due to a particularly positive experience or a particularly difficult one. In this sense, research may not represent the views of those who had fairly middling experiences. Consistent with Willig's (2008) advice, I asked each participant about their motivation for volunteering. As anticipated by Rozmovits and Zeibland (2004), and Nelson (2010), three participants said they wanted to volunteer because they wished to espouse positive accounts of mindfulness and MBIs. For example, Nadia said she found the mindfulness course really helpful and wanted to "promote [mindfulness] as a technique" (line 17). One participant, Harriet, explained she wanted to ensure that negative experiences were represented in my dataset too. She said, "I thought you might be very pro-mindfulness or something and I hadn't had a brilliant experience" (21-26).

Since only three out of eight participants espoused particularly positive or negative accounts, it could be suggested that the current findings do describe the views of

those who had more middling experiences. Certainly, when we consider other reasons participants gave for volunteering we can see that having a particularly positive or negative experience was not at the forefront of many accounts. No individuals gave just one reason for volunteering. Indeed, six said they wanted to volunteer because they felt ME/CFS was poorly understood and research in the area scarce. For five participants, this was the motivation they mentioned first, which perhaps indicates it was the one most important to them. Participants noted a range of other reasons for volunteering too. These included being interested in the area (two participants) and desiring to help me (one participant). Other reasons given were that the interview was an opportunity to explain their experience (one participant) and believing that talking about their experiences would help them (two participants). It seems that individuals in the current study volunteered for a variety of reasons. Thus, their accounts may not be meaningfully different from others with more middling experiences.

A brief criticism of the current study can be made relating to the demographic information gathered. Information collected did include the severity of participants' symptoms, both at the time the data was gathered and in general. However, perhaps a more useful piece of information would have detailed the severity of symptoms at the time of the course. We know ME/CFS to be a fluctuating illness (Arroll & Senior, 2008) and cannot therefore conclude that the general measure of severity would be representative of the time participants' courses ran. Indeed, Caroline, Daniel, Irv, and Lucy all described their symptoms at interview as being much better than at the time of the course. Knowing at what level of severity participants would have classified their illnesses at the time of their MBIs may have added an extra layer to our understanding of their experiences. It may also have provided an avenue for me to explore during interviews.

Another criticism of the current study pertains to ethics. As discussed in the Methodology section, researchers such as Willig (2013; 2012), Kvale (2003, as cited in Willig, 2012), and Latour (2000, as cited in Willig, 2012), argue that it is important for participants to be able to object to what is said about them. I would suggest that being able to object to interpretations is particularly important in the area of ME/CFS. Historically, ME/CFS patient populations have objected to research findings published about their condition. Rather than this leading to opening a dialogue between researchers and people with ME/CFS, it seems to have created more of a battle in some circles. As mentioned earlier, a rift seems to exist between psychologists and some individuals and groups with ME/CFS. Again, as discussed earlier, this battle stance might mean individuals are restricted from accessing treatment options which could be helpful to them. In light of the above, it seems it would have been more ethical if I had engaged in 'member checking' whereby interpretations are taken back to participants and amended as appropriate. Not only might this have ensured that participants' experiences were less likely to be misrepresented, but it may also have communicated that psychologists are willing to listen and desire to give people with ME/CFS a voice. Unfortunately, due to the limited time for this research, I was unable to do this. However, I would advocate member checking whenever possible in research conducted within the ME/CFS field.

#### ***4.8 Future research***

Numerous ideas for future research arose from the present study. First, it may be useful to investigate whether the 'ME/CFS-fact or fiction' discourse is more prevalent in MBIs where intervention falls more obviously into the realm of psychology, for example in personal therapy. Studies could consider if and how the discourse is represented, and the implications for clients' experiences, outcomes, and engagement. Second, it may be interesting to explore people with ME/CFS's

understandings of how mindfulness ‘works’, particularly the mechanisms through which it impacts on their symptoms. It may be useful to see whether participants classify mindfulness as embodying psychological change mechanisms and to consider how this fits into individuals’ conceptualisations of their illness aetiology. In turn, it may be beneficial to learn about whether such conceptualisations impact engagement with MBI and people’s opinions on the potential of mindfulness for them.

Third, I wonder if it would be useful to explore the responses of people with ME/CFS and patient organisations to research publications which suggest psychological influences on ME/CFS. In particular, it may be interesting to ask people to read two articles – one which might be considered ‘validating’ and another which might be considered ‘less validating and more clinical and academic’. Researchers could interview people about their responses to each article, investigating participants’ thoughts around the research findings and how valid or accurate these might be. Perhaps this would be an interesting study to complete as it may provide us with information to bridge the gap between research findings and some clients’ rejections of these. Information that could bridge this gap might have a number of implications. For example, it might mean that individuals are better informed as to the options available to help them and it may help to repair the relationship between some in the ME/CFS population and the psychological profession. It may also help to increase the reputation of psychologists in some areas of the ME/CFS population.

Fourth, perhaps it would be helpful to investigate further the role of hope in MBI outcome. Hope has been considered by many in the psychology literature, particularly in terms of its impact upon therapeutic success. Research suggests that hope and change are strongly connected (e.g. Glassman, Kottsieper, Zuckoff & Gosch, 2013; O’Hara, 2013; Alarcón & Frank, 2012; Irving et al., 2004). Indeed,

Irving et al. (2004) suggest that the more hopeful a person is, the better their therapeutic outcome is likely to be. This is thought to be the case in group-therapy too (Yalom & Leszcz, 2005). The theme of hope appeared to run through the accounts of many of the present participants as they talked about their pre-course expectations for outcome and evaluating the course in terms of these expectations. Throughout the current discussion I have drawn a link between beliefs about psychological aetiology and hope for change, suggesting that believing in a psychological aetiology may mean individuals have more hope that MBIs have the potential to help them. I also suggested that perhaps experiencing improvements first-hand makes individuals more likely to see potential in psychological interventions. Moreover, I have considered participants' experiences of their facilitators' passion and also linked this to hope. Passion may be seen as a positive quality if participants felt hopeful the MBI could help them. I have spoken further of managing expectations for MBIs from the beginning of the process, and how this might be important for engagement and outcome. Perhaps researchers could focus on further exploring the factors which affect hope for individuals with ME/CFS in the MBI context, and elicit positive changes in it.

Fifth, it could be interesting to explore what variance in positive MBI outcome is attributed to the group and what variance is attributable to the mindfulness material. Moreover, researchers could investigate further what elements of the group and what elements of the material contribute particularly to outcome in ME/CFS populations. In this way, we could learn what might be most helpful to harness so individuals can be assisted to gain the most possible from interventions.

Sixth, as argued in the Introduction, 'acceptability' data may be biased when collected only from individuals who completed interventions, not those who dropped out or were excluded at outset. A similar principle can be considered in the present research. The current study included only participants who had attended six or

more of the sessions. It is reasonable to assume that data might be quite different if gathered from individuals who dropped out of courses early. Indeed, other research has found pre-MBI differences to be related to drop-out. For example, Crane and Williams (2010) looked at attrition rates for individuals attending MBCT who had a history of suicidal depression. They found that individuals who dropped out scored higher on measures of brooding, cognitive reactivity, and depressive rumination at baseline. Although this sample might be quite different to populations of individuals with ME/CFS, it shows the possibility of baseline differences influencing dropout rates. In particular, it highlights the possibility of thought patterns influencing attrition. Therefore, future research may benefit from exploring experiences of MBI for individuals with ME/CFS who dropped out of interventions prematurely. This might shed further light on barriers to engagement and the process of overcoming or not overcoming these.

Seventh, as we have seen, it may be that 'ME/CFS' is an umbrella term which encapsulates different subsets of individuals. It could be that these subsets differ in the importance they place on certain phenomena, or experience phenomena in categorically different ways. For example, we might expect participants categorised by more physical symptomatology to speak more about mindfulness as a strategy to manage muscle soreness or pain. Similarly, we might expect those with co-morbid psychiatric conditions to speak more about using mindfulness to manage mood and emotional difficulty. Therefore, it may be useful for future research to screen participants according to these different categories, then interview individuals within each subset. Considerations for the teaching of mindfulness and utilisation of MBIs might emerge from such analysis. In light of the findings, it might be that best practice would be to screen participants and offer them MBI designed specifically to address issues more prominent in their subgroup. Perhaps this would maximise the effectiveness of MBI for these individuals.

Eighth, the literature might benefit from research into MBIs for individuals with ME/CFS which uses more homogenous samples. I believe the sample used in the current study was sufficiently homogenous for the aim of the research and to provide meaningful findings. Indeed, themes in the current research appeared common across accounts despite the age, time of symptom onset, and symptom severity that participants reported. For example, a participant who had been more recently diagnosed appeared to feel loss just as keenly as another diagnosed for many years. However, it is not unreasonable to assume that experiences would hold different essences for participants from differing demographics. For example, experiences may differ between one who has experienced symptoms for a short time, compared with one who has experienced symptoms for a significant amount of years. Indeed, Deringer (1992) reported that the longer the women in her study had ME/CFS, the more they were able to integrate the illness into their self-image. Consequently, participants' lives were reported to become more rewarding the longer they lived with the illness. Similarly, Asbring (2001) reported that women who had experienced ME/CFS for longer seemed further along in a 'coming to terms' process. Experiences may also be different between one whose symptoms (and limitations) are particularly severe, and one whose symptoms could be classed as mild. Similar to focussing on different symptom or aetiology subgroups, perhaps future research could focus on illuminating the experiences of MBIs for particular demographics. Again, the findings from such studies could be used to shape interventions and maximise the potential effectiveness of MBIs.

Ninth, it seems that research into ACT and ME/CFS is warranted. As advocated by Brooks et al. (2011), a randomised control trial design may be helpful to establish whether ACT could reduce symptoms and disability associated with ME/CFS for a large number of people. I would suggest that researchers also investigate whether ACT can increase quality of life. A comparison of this against traditional CBT for

ME/CFS might be interesting. Moreover, it may be useful to consider whether successful outcomes in ACT can be attributed to an integration of the desired or anticipated self into the current 'ill' self.

#### ***4.9 Final summary***

Overall, we have seen that participants in the current study appeared to frequently adopt an ME/CFS lens. As a result, we might expect anxiety around MBIs to be high. Best practice could be to reduce this anxiety, particularly by reducing the activity required from MBI sessions. We know stigma to be particularly prevalent in the area of ME/CFS and can expect individuals with ME/CFS attending MBIs to be aware of this. In contrast to other approaches, we have found that MBIs may not automatically be judged as delegitimising clients' conditions. To ensure that such a barrier is not erected, facilitators could ensure that MBIs avoid 'psychological' marketing. Facilitators could also work to actively communicate understanding and sensitivity towards the condition.

We have noted that relationships are crucial to engagement with and gaining from MBIs. Peer relationships appear to encourage perseverance, promote a sense of normality, and provide a source of information and support. It may be advisable for practitioners conducting MBIs to harness the power of the group. We have also found that the facilitator plays an important part in the MBI experience. Particularly, showing caring and giving clear guidance was thought to encompass best practice. The current study found that acceptance, in many forms, was an important and valued aspect of individuals' experiences. Such findings seem to reflect those in the wider literature. We can conclude from the discussion that Acceptance and Commitment Therapy (ACT) may be a particularly helpful resource for individuals struggling with ME/CFS.

Some of the barriers reported in the current study are also echoed in the wider literature. It seems that working with, rather than against, individuals' religious beliefs is advisable. Similarly, managing individuals' expectations at outset may increase the benefits individuals could gain from MBIs.

The current study may be limited in its clarity, and due to its sampling methods. Ethics could also have been improved upon by the inclusion of member checking. Future research might focus on further exploring 'ME/CFS-fact or fiction' discourses around MBIs and published literature. Investigations might also focus on the role of hope in MBI outcome. Studies could further explore what variance in MBI outcome for people with ME/CFS can be attributed to the group exchange. It may also be interesting to conduct research with participants who have dropped out of MBIs early and with different subsets of the ME/CFS condition. Studies could look at exploring the experiences of certain ME/CFS demographic groups relating to MBIs. Finally, future research into the utility of ACT for ME/CFS and the mechanisms within this appears warranted. The current study has certainly provided us with some interesting and useful data, as well as exciting avenues for future investigation.

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## **Part Two – Publishable piece**

### ***“I was quite a cynic initially”: People with ME/CFS’ struggles with doubts and understanding in mindfulness-based interventions***

#### **Abstract**

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) affects approximately 150,000 to 250,000 people in the UK and is characterised by wide-ranging physical and cognitive symptoms. Fatigue is thought the most common symptom amongst others, such as ‘cognitive dysfunction’, sore throat, swollen glands, digestive problems, sleep difficulties, pain, and headaches. Literature suggests that people with ME/CFS often experience substantial loss and find living with the condition emotionally challenging. Mindfulness-based stress reduction, mindfulness-based cognitive therapy, and adaptations of these, have been found helpful for many of these symptoms and emotional difficulties in a wide variety of samples. Research also indicates promising results in ME/CFS populations. The current article explores ‘Struggling with doubts and understanding’, one of four themes generated from the researcher’s doctoral thesis. Eight participants were interviewed regarding the question, ‘How are mindfulness-based interventions experienced by people with ME/CFS?’ Interpretative Phenomenological Analysis was chosen to analyse the data. Two subthemes, ‘Scepticism, cynicism and doubt’, and ‘Facilitator-related barriers’, were collated under the master theme. Doubts centred on whether the techniques would ‘work’, whether facilitators would have religious or covert agendas, and the apparent simplicity of techniques. Hesitations were also centred on the perceived similarity of mindfulness to relaxation, and mindfulness’ mechanisms of change. The facilitators’ guidance, client focus, and religious considerations appeared to act as barriers or enablers towards

engagement and attendance. Facilitators may benefit from considering expectations before and during interventions with the aim of managing 'expectancy violation', reducing distress, and helping maintain hope for beneficial outcomes. The study is critiqued on sampling and ethical considerations.

### **Key words**

Myalgic encephalomyelitis, chronic fatigue syndrome, mindfulness-based interventions, interpretative phenomenological analysis, barriers, scepticism

### **1. Introduction**

The current paper seeks to elucidate findings from a larger study. The larger doctoral thesis asked how mindfulness-based interventions (MBIs) are experienced by people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Four superordinate themes were highlighted and the second theme, Struggling with doubts and understanding, was chosen for elaboration in the current article.

ME/CFS is thought to affect approximately 150,000 to 250,000 people in the UK (Shepherd & Chaudhuri, 2011). The likelihood of full recovery is estimated as low (Poppe, Petrovic, Vogelaers & Crombez, 2013; Cairns & Hotopf, 2005). Cairns and Hotopf (2005) found a median full recovery rate of seven percent, and reported that just under 40% of the individuals in their study appeared to experience improvements rather than full recovery.

The aetiology of ME/CFS appears a contested subject. Many researchers adopt a bio-psycho-social attitude (Poppe et al., 2013; Eglinton & Chung, 2011), the stance taken by the current researcher too. There is a substantial body of research to suggest that psychological factors can influence symptoms (Wearden & Emsley, 2013; White et al., 2011; Deary & Chalder, 2010; Chalder, Neeleman, Reme, Power & Wessely, 2010; Moss-Morris & Petrie, 2000). There is also research which indicates biological differences in ME/CFS samples, indicating a likely neurological

aetiology (disorder of the nervous system) (Morris & Maes, 2013; World Health Organisation [WHO], 2007). Literature also commonly reports that social factors, such as stress and adverse life events, can contribute to onset and symptom exacerbation (Prins, van der Meer & Bleijenberg, as cited in Perry & Santhouse, 2012; Moss-Morris & Petrie, 2000).

People with ME/CFS appear to experience a range of symptoms. According to Fukuda et al. (1994) the most common symptom is severe and disabling fatigue. Without this, Fukuda et al. (1994) argue that a diagnosis of ME/CFS cannot be made. One participant in a study by Arroll and Senior (2008) described fatigue as a “lack of stamina” rather than a tiredness (p. 448). Fatigue was felt to be about tiring quickly rather than being tired all the time. Individuals report that fatigue manifests in their muscles, as well as in what is commonly known as ‘cognitive dysfunction’. Here, individuals describe difficulties with poor concentration, problem solving, word finding, and loss of memory (Morris & Maes, 2013; The ME Association [MEA], 2010; Arroll & Senior, 2008; Lovell, 1999). Other commonly reported symptoms include sore throat, swollen glands, digestive problems, pain, headaches, and poor or dysregulated sleep (Morris & Maes, 2013; Dickson, Knussen & Flowers, 2008; Shepherd, 1998).

Not all individuals diagnosed with ME/CFS will experience all of these symptoms. Symptoms are also known to vary in everyday life, sometimes for no apparent reason and other times as a result of activity (Arroll & Senior, 2008). Research has indicated that even trivial increases in physical or mental activity above a certain level of tolerance can result in symptom exacerbation. The line between what can and cannot be tolerated appears subjective and often mysterious (Arroll & Senior, 2008), and thus exacerbation is not always predictable or controllable. Since experiences of ME/CFS can be so varying, some researchers have been prompted to suggest that ME/CFS is in fact an umbrella term encapsulating different subsets

of severities, symptom clusters, and aetiologies (see Brown, Jason, Evans & Flores, 2013; Jason et al., 2012; Sullivan, Pedersen, Jacks & Evengard, 2005; and Jason, Torres-Harding, Jurgens & Helgersen, 2004.)

There is much research to suggest that developing ME/CFS and living with the condition can be emotionally challenging. Studies have found that individuals report a substantial amount of loss. For example, researchers have reported losses of role, relationships, employment, and hobbies (Dickson et al., 2008; Dickson, Knussen & Flowers, 2007; Moss-Morris & Petrie, 2000). Individuals have also reported a loss of identity, describing themselves with ME/CFS as not their 'true' selves and mourning the selves they once were or once expected to be (Brooks, Wearden & King, 2014; Dickson et al., 2008; Asbring, 2001). As we might expect, studies have also reported high occurrences of low mood in individuals living with ME/CFS. A plethora of research reports individuals experiencing emotional distress as a result of living with the condition (Eglinton & Chung, 2013; Anderson, Jason, Hlavaty, Porter & Cudia, 2011; Shepherd & Chaudhuri, 2009; Arroll & Senior, 2008; Dickson et al., 2008; Ward, Hogan, Stuart & Singleton, 2008; Lombaard & Mouton, 2005; Komaroff et al., 1996).

The term 'mindfulness' can be seen as an umbrella one as different authors and researchers appear to conceptualise mindfulness in varying ways. For the current research, mindfulness was operationalised in the context of MBIs. Although the term 'MBI' is used in the literature (e.g. Vago & Silbersweig, 2012; Grabovac, Lau & Willett, 2011), this author was unaware of any established definition. The researcher's own description was therefore developed. MBIs were classified as "an experience which involves formal mindfulness practice, as well as communication with an individual whose role is to introduce mindfulness theory and practice". Formal practice was defined as "sitting/lying and paying attention to the present moment without judgement".

Many existing and established therapeutic approaches are encapsulated by this definition. Those important for the current paper are mindfulness-based stress reduction (MBSR), mindfulness-based cognitive therapy (MBCT) and interventions adapted from and based on these models. All current participants appeared to have engaged in some version of the above. MBSR is a group-based treatment protocol that was developed by Jon Kabat-Zinn in 1979 (Cullen, 2011). It is delivered over eight weeks and designed for individuals with a variety of difficulties, including chronic pain, hypertension, heart disease, cancer, gastrointestinal disorders, anxiety, and panic (Prince of Wales International Centre, n.d). Cullen (2011) states that MBSR uses three formal meditations (mindful movement, body scan, sitting meditation), and promotes regular practice and the application of teaching in daily life.

MBCT is also a treatment protocol delivered in a group format over eight weeks. It is based on Kabat-Zinn's MBSR programme and was developed by Zindel Segal, Mark Williams, and John Teasdale early this century (Segal, Williams & Teasdale, 2002). MBCT was specifically designed to help individuals experiencing repeated periods of low mood learn relapse prevention skills (Prince of Wales International Centre, n.d; Malpass et al., 2011). According to Grabovac et al. (2011) MBCT focuses on decreasing rumination by developing awareness of cognitions or sensations and our thoughts about these. Clients are encouraged to respond consciously to cognitions or sensations with self-care. This could mean purposely switching attention to a neutral focus, or deliberately engaging in activity which provides pleasure or a sense of efficacy (Grabovac et al., 2011).

A plethora of research has found these MBIs to be helpful for the symptoms and experiences we know many individuals living with ME/CFS to encounter. For example, MBSR has been found helpful for individuals experiencing pain (Lauche, Cramer, Dobos, Langhorst & Schmidt, 2013; Rosenzweig et al., 2010), fatigue

(Carlson & Garland, 2005), mental fatigue (Johansson, Bjuhr & Ronnback, 2012), irritable bowel-syndrome (Garland et al., 2012; Kearney, McDermott, Martinez & Simpson, 2011), headache (Schmidt, Simshäuser, Aikin, Luking & Schultz, 2010), and sleep (Frank, Reibel, Broderick, Cantrell & Metz, 2013; Gross et al., 2011; Carlson & Garland, 2005). MBSR has been found to help low mood (Gold et al., 2010; Carlson & Garland, 2005), anxiety (Gold et al., 2010), and stress (Gold et al., 2010; Carlson & Garland, 2005).

Similarly MBCT has been found to be helpful for individuals experiencing pain (Bedard et al. 2012), fatigue (van der Lee & Garssen, 2012), working and spatial memory, and verbal fluency (Ives-Deliperi, Howells, Stein, Meintjes & Horn, 2013), headache (Day, Thorn & Rubin, 2014; Day et al., 2014), and sleep (Yook et al., 2008). MBCT has been found to help low mood (Britton, Shahar, Szepsenwol & Jacobs, 2012; Chiesa & Serretti, 2011), anxiety (McManus, Suwary, Muse, Vazquez-Montes & Williams, 2012; Chiesa & Serretti, 2011), and stress (Britton et al., 2012).

Each of these studies used samples other than individuals with ME/CFS. It appears that little research exists exploring the usefulness of MBIs for people living with this particular condition. Those studies that have been conducted indicate promising results. For example, Surawy, Roberts and Silver (2005) found MBSR and MBCT to have beneficial effects upon anxiety, depression, physical functioning, fatigue, and quality of life. Similarly, Sampalli, Berlasso, Fox and Petter (2009) found an adapted MBSR programme to be related to improved scores in somatisation, depression, phobic anxiety, paranoid ideation, obsessive-compulsiveness, interpersonal sensitivity, anxiety, and psychotic responses. Finally, Rimes and Wingrove (2011) found MBCT to elicit improved scores on fatigue, beliefs about emotions, catastrophic thinking, 'boom and bust' behaviour, self-compassion, impairment and depression measures.

A small body of research has also considered the role of acceptance in ME/CFS. Acceptance is thought to be integral to mindfulness, being seen as associated with mindfulness philosophy and mindfulness practice (e.g. Coffey, Hartman & Fredrickson, 2010; Harris, 2009). Bogaerts et al. (2007) found individuals to report lesser 'negative' emotion, and fewer subjective complaints of hyperventilation and symptoms such as headache when engaging with acceptance imagery. Participants were also reported to display no physiological hyperventilation when engaging with this imagery. Brooks, Rimes and Chalder (2011) found that lack of acceptance was associated with poorer physical functioning as well as lower work and social adjustment. Lack of acceptance was also related to depression, and two facets of perfectionism – concern over mistakes and doubts about actions. Qualitative literature suggests that acceptance can play a central role in adjustment to living with ME/CFS (e.g. Dickson et al., 2008). Interventions such as MBCT and MBSR which seek to cultivate acceptance may therefore be particularly useful for people with ME/CFS.

Apart from this researcher's doctoral thesis, the current author is unaware of any qualitative literature investigating MBIs and ME/CFS together. Such research appeared warranted. Any investigation giving further insight into the experience appeared a worthwhile endeavour due to the plethora of findings suggesting MBIs to be helpful for people with ME/CFS. Moreover, there appeared to be a paucity of information which could be meaningfully used to guide those facilitating MBIs for people with ME/CFS in best practice.

Surawy et al. (2005) and Rimes and Wingrove (2011) did collect some information about how participants experienced the MBIs with which they engaged. Surawy et al. (2005) used a Likert scale asking participants to rate course components from 0 (not at all useful) to 10 (very useful). Rimes and Wingrove (2011) asked participants to answer the question 'how useful has the mindfulness course been to you?' with

options of 'no use at all', 'quite useful', 'moderately useful', and 'very useful'. Although Rimes and Wingrove (2011) seemed to collect some qualitative data, this appeared to centre specifically on home practice and was not discussed further in their write-up.

Although such measures can give some insight into how MBIs were experienced, the data they gather is understandably restricted. In contrast, this topic appears complex and multifaceted. It seems to require methodology which allows for spontaneous and complicated responses. For example, individuals may speak about how appropriate the MBIs felt in regard to their religious backgrounds, as well as perceptions of the facilitators' attitude and teaching styles. Participants might also consider necessary, and perhaps unwanted, adaptations they were required to make to their lives to incorporate sessions and home practice into their routine. The original study therefore adopted a qualitative approach as this aims to understand how people make sense of their worlds and experience particular phenomena. Interpretative phenomenological analysis (IPA - Smith, 1996) was chosen specifically due to its phenomenological commitment – to examine lived experience and focus on what is important to the individual.<sup>11</sup> Indeed, findings painted a complex portrait of MBIs and the elements participants found to influence their experience.

The theme chosen for exploration in the current paper, 'Struggling with doubts and understanding', was selected for dissemination above the other themes espoused in the original paper for two reasons. First, the findings appeared especially pertinent to client outcome from MBIs and thus were considered particularly important. Second, findings had a practical feel and practical steps that facilitators

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<sup>11</sup> IPA was also chosen because it was thought compatible with the researcher's epistemological beliefs. She adopted a 'critical realist' stance, which Willig (2008) considers to be compatible with the IPA method of analysis.

could take to enhance client engagement emerged from the analysis. The findings and subsequent discussion of them was therefore felt particularly constructive for readers.

## **2. Method**

### ***2.1 Recruitment***

Recruitment was conducted via two methods. First, the study was advertised during a talk given by the researcher to an ME/CFS support group. Second, individuals were recruited via a round-robin email sent from a local mindfulness organisation. Individuals were given a recruitment flyer initially then a more detailed information sheet on first contact.

### ***2.2 Sample***

Smith, Flowers and Larkin (2009) give a clear and detailed account of how to conduct IPA. They suggest that samples should be chosen to give data that answers one's research question and is homogenous, so findings can be considered with other findings from similar samples. Accordingly, participants met the Fukuda et al. (1994) criteria for ME/CFS and had experienced MBIs consistent with the aforementioned definition. All participants described MBIs consistent with an MBSR or MBCT style, and had engaged in these for at least six weeks.

Five females and three males were interviewed. The average age of participants was 49.4 years, (a range from 36 to 66 years). Seven participants identified as 'white-British' and one 'Asian-white'. Individuals described experiencing ME/CFS symptoms for an approximate average of 14 years 5 months, (a range from 3 to 25 years 6 months). One participant described his ME/CFS as generally severe, four as 'moderate', one 'mild-moderate', and two 'mild'. All had engaged in at least one course incorporating mindfulness, attending a minimum of seven or eight sessions. Four had either practised mindfulness or meditation or read up on the subject

before attending a formal intervention. Four had engaged with further courses, classes, or sessions following their initial intervention.

### ***2.3 Interview schedule and process***

The interview schedule was developed in accordance with the five-step procedure suggested by Smith et al. (2009). Questions were designed to gather data about participants' experiences of the concept of MBIs, their experience of the practice of MBIs, and their experiences of life with ME/CFS during and after MBIs. In accordance with Willig (2008) the researcher aimed to find out what the interview meant to interviewees. Consistent with Robson (2011) a 'cool off' period was utilised towards the end of interviews. General prompts were also prepared (Smith et al., 2009). Questions were designed to elicit answers grounded in individual experience and aimed to make as few assumptions as possible about what may concern participants or be important to them. Opinions of participants and colleagues were considered in the development of the questions. The completed schedule is available in Appendix P.

Willig (2008) and Smith et al. (2009) explain that the success of the semi-structured interview depends on the rapport developed between interviewer and interviewee. In light of this, participants were briefed before the interview regarding what the process might be like. The researcher aimed to ease participants into the interview with less sensitive topics and prompted individuals should they show anxiety or confusion. Consistent with advice given by Smith et al. (2009) the interviewer made use of verbal and non-verbal encouragement, and aimed to speak slowly and clearly.

The researcher sought to enter participants' worlds during the interviews, thus created new questions based on the data individuals were giving throughout. The researcher aimed to be flexible, using her schedule as a guide rather than a rigid

structure and following avenues that appeared important to participants. As many assumptions as possible were bracketed during this process.

Data were recorded via Dictaphone and transcribed by the researcher herself. As well as words, pauses in speech, laughter, and false starts etc were noted. Identifying information was changed at this point to ensure confidentiality.

#### ***2.4 Analytic procedure***

Again analysis was conducted in line with advice given by Smith et al. (2009). As is expected, some adaptations to the process were made according to the researcher's aim and topic of interest.

In particular, a 'body-focus' was adapted into the analytic process. Rationale for incorporating this centred on appropriateness to the research topic, the generation of deeper and richer findings, and the assisting of the bracketing process. In practice, body-focus meant maintaining a conscious present-focussed awareness of bodily sensation and cognitive thought throughout analysis, as much as possible.

Analysis consisted of reading and re-reading the transcript whilst listening to the recording. Initial thoughts and observations were noted during this phase. In-depth and thorough notes were then made on the transcript and considered descriptive, linguistic, and conceptual paradigms (see Smith et al., 2009). Following this, emergent themes were developed. A 'theme' was considered to be "a concise and pithy statement of what was important in the various comments attached to a piece of transcript" (Smith et al., 2009. p. 92). Here, a further stage was added, the reconsideration of emergent themes against the original recording. Body-focus was particularly important during this step, the researcher noticing whether themes felt 'right' and 'fitted' with what she felt from the recording. Such a process might be labelled 'focussing', written extensively about by Eugene Gendlin (e.g. Gendlin, 2003).

Next, emergent themes were printed onto smaller pieces of paper and similarities between them considered. Like-for-like was clustered together and at times emergent themes were considered better placed as superordinate ones. Key events were considered in the grouping, as was the frequency of which emergent themes arose. Themes were also clustered according to what the researcher imagined participants were trying to achieve by their narrative. These processes are described as 'abstraction', 'subsumption', 'numeration', and 'function' by Smith et al. (2009, chapter five). Once clusters had been created, a table of themes was generated for each participant. During this stage, the research question was kept at the forefront of the process and themes which appeared irrelevant gradually discarded.

Tables of themes were then considered against each other and connections between them investigated. A final table of themes was created and from this an initial draft written. Researchers frequently highlight that writing-up is part of the process of analysis (e.g. Smith et al., 2009; Braun & Clarke, 2006). Indeed, many themes were adapted and developed throughout the writing process until the narrative was thought sufficiently interpretative and useful to the reader.

### ***2.5 Ethics of interpretation***

Willig (2013; 2012) explains that interpretation is always a process of transformation. The interpreter is considered to generate their version of the 'truth'. Interpretation is therefore believed to be an act which holds much power (Willig, 2012). The researcher's version of reality is thought to restrict and shape the responses that readers can have to the material. Their interpretations can hold consequences for both the person whose data has been interpreted, and for wider society. Consequently, the present researcher aimed to remain reflexive throughout the process, bracketing her preconceptions as much as possible. She attempts to

be modest about what the study can reveal and means for her analysis to be conceptualised as *an* interpretation, not *the* interpretation.

### 3. Findings

“I was quite a cynic initially” (Lucy: line 317)<sup>12</sup>

The theme ‘Struggling with doubts and understanding’ considers the psychological and practical barriers participants reported experiencing when engaging with their MBIs. *Scepticism, cynicism and doubt* considers when participants described lacking belief in the interventions, where their disbelief was directed, and what this was like for them. In *Facilitator-related barriers* we reflect on barriers to engagement focused solely around therapists.

#### 3.1 *Scepticism, cynicism and doubt*

At least seven participants described encountering the course and the material with reservations. Three expressed being doubtful before the course began that the techniques would be useful. Irv said:

“When someone says ‘but if you learn to breathe correctly or in a more appropriate fashion [or] beneficial way you will see a difference’ [] I’d read about it but I didn’t really think it would make any difference.” (Irv: 1073-1081)

This is somewhat similar to Lucy, who described almost not attending the intervention because she anticipated it would not help her:

“I almost didn’t go cos I thought this isn’t really going to help”. (Lucy: 184-186)

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<sup>12</sup> Quotes are referenced ‘participant: line number’. Some words have been deleted from participants’ accounts for the purposes of coherency. All participants chose their own pseudonyms. The symbols ‘[ ]’ indicate that material has been omitted, and ‘[text]’ refers to explanatory material added by the researcher. ‘-’ indicates that a word was started and not finished, and ‘...’ shows that the interviewer’s speech has been removed.

Daniel also spoke of doubts potentially affecting attendance. He referred to religion and anticipating that facilitators might attempt to impose this on their attendees:

“Some people might think, ‘oh my gosh you go to somewhere like that and they’re going to try and er convert you to Buddhism’ [] ... [] I wondered at first whether it would be like that.” (Daniel: 779-811)

It seemed that eventually none of these reservations impacted upon the above individuals’ engagement with the course or material in the long-term. Each participant described themselves as gaining from what they were taught. Whereas Lucy and Daniel’s reservations appeared to diminish during the course, Irv remained sceptical of the material throughout, experiencing a change of heart some months after. For Irv, it was the perceived simplicity of the techniques which acted as a barrier, leading him to conclude that they were not “useful”:

“They didn’t really register as being useful, in fact quite often I felt resentful because I was being told things that sounded so fundamental [] I thought, ‘well, I want to hear something a little bit more technical’.” (Irv: 290-298)

Interestingly, after time, the simplicity of the techniques changed from a barrier to an enabler:

“I then some months later realised that its simplicity that is the key. It’s not too difficult to learn to breathe properly, it’s not too difficult to have a pattern of relaxation, and it benefits you immensely.” (Irv: 298-306)

It seems that it was the application of the techniques and actually experiencing benefits that led to Irv’s reappraisal. Unfortunately, Harriet had quite a different experience. Her hopes for the course remained unmet as she lacked connection

with the material and noted little improvement. Harriet described remaining cynical throughout the course, continuing to be doubtful at the interview. Harriet seemed to have missed the essence of mindfulness, understanding mindfulness and relaxation as the same thing:

“It’s relaxation [] it’s nothing new”. (Harriet: 1130-1138)

Since Harriet had practised relaxation for many years, this misconception appeared to be a significant block for her, leading her to conclude that there was nothing more she could get out of the practices than she already had. Not only did this appear hugely disappointing for Harriet, but, understandably, she became angry about what she perceived as repackaging and the exploitation of herself and others:

“I thought that’s ridiculous ... [] they’re presenting it as something new and people have been taken in by it”. (Harriet: 1174-1183)

As one might imagine, it seemed Harriet’s trust in the MBI organisers or developers was damaged. She described guessing at the agendas behind the exercises she felt confused by and thinking the worst. Part of Harriet seemed to conclude that underlying the course was the assumption that individuals were fabricating the nature or severity of their condition:

“What’s the point of it? [] Are they trying to get us fitter because we’re quite out of condition?” (Harriet: 1305-1308)

For two participants, Richard and Harriet, scepticism seemed to be a part of their identity that they could not switch off. Richard said:

“My main personal characteristic is this sceptical one. I think in some ways it’s kind of preventing me from totally accepting it [mindfulness] as a philosophy and perhaps getting more out of it.”  
(Richard: 1837-1846)

There seemed wistfulness in Richard's account, a yearning to let go of his scepticism and reap the benefits he saw others on the course experiencing. Likely based on his observation of his course peers, Richard seemed to believe that if one could truly give oneself to mindfulness it might dramatically change one's life. Richard talked of a way he might be able to put more faith into the techniques:

"I would like to have a better intellectual understanding of the evidence for its benefits, so that I can put that against my personal experience of it, and perhaps enrich it, and say well, you know, there is good research evidence for doing this therefore I should apply more." (Richard: 1861-1874)

Richard seemed to be ignoring his personal experience that he found, and continued to find, some of the techniques unhelpful. In a sense, Richard appeared to appraise his experience and what his body was telling him as unimportant. It seems Richard was searching for an academic "truth", a truth which advocated mindfulness and one in which he could believe more than his own experience.

Harriet espoused a similar experience. She spoke about scepticism as part of her identity and described questioning whether her facilitator and peers were experiencing a placebo effect:

"They just seem to believe so wholeheartedly that it will help them and it has [] and you think, well I don't know what came first." (Harriet: 503-508)

She also questioned whether timing was a mechanism of change:

"It just changed her life, you know. It made a huge difference, and part of me thinks, ah, it was just the ri- it was just that particular time, wasn't it." (Harriet: 455-461)

Like Richard, Harriet seemed to subscribe to the belief that, if one could truly give oneself to mindfulness, it might make a huge difference to one's life. Again, contained within Harriet's account is a sense of wistfulness. It seemed Harriet wished she could put faith in mindfulness the way she perceived others to, because she desperately desired for herself the benefits others seemed to have gained:

"I blame myself, and think if I'd done that it might have helped me more". (Harriet: 509-512)

### **3.2 Facilitator-related barriers**

It appears obvious that facilitators had an enormous influence on individuals' perceptions of mindfulness and its potential. Six participants spoke about the facilitator acting as a barrier. Whereas Daniel reported later that his pondering about religion was unfounded, Harriet described a different experience:

"She'd end with saying 'amen' and put her hands together. Now that unnerved me slightly because I thought, 'does she mean amen in a sort of Buddhist type thing?' [] it confused me as to where she was coming from and what sort of course it was." (Harriet: 2240-2255)

Harriet felt uncomfortable, wondering whether her facilitator was trying to engage her in a Buddhist act. She described not joining in with the "amen", and noting whether other members of her course did the same. As a result, her attention appeared to be focussed away from actual engagement with the practice.

In questioning the religious agenda behind her facilitator, Harriet seemed to perceive her teacher's agenda as one not focussed on the client. Caroline also doubted whether her facilitator's intentions were driven by the needs of the participant. She spoke about perceiving her facilitator to prioritise time above the capabilities of her students:

“Sometimes the person on that side is just governed by a clock, or a period of sessions, and that’s not the way it should be because that puts you, instantly you [feel] like you’ve got to deliver [] and you can’t just deliver it like that.” (Caroline: 1348-1356)

Caroline explained that, in her quest to perform for her facilitator, she was unable to use exercises in the way she wished. Caroline appeared to refer to the body scan. In particular, she described being unable to spend the time she wanted exploring particular body parts. She reported being unable to be with them as they were, instead feeling pressured to experience something specific:

“You think, right, I’ve gotta feel this in this toe”. (Caroline: 1374-1376)

It seemed that counter to what is advocated by much of the mindfulness literature, Caroline was not observing with an attitude of curiosity. Rather, she was seeking with a narrowed and expecting perspective.

Participants also talked about the guidance their facilitators gave them and how this could act as a barrier or an enabler. Harriet spoke about not connecting with the metaphors her facilitator talked about, lacking understanding of the concepts behind them:

“She sort of had techniques that you’re supposed to think of, like water and things [] but I felt once we’d been given the idea it was just left and we weren’t quite sure how to apply it.” (Harriet: 248-255)

It seemed Harriet had felt some instruction was missing – “it was just left”. Harriet appeared to feel she lacked guidance on how to apply the theory that the class had been introduced to. Patricia espoused a similar experience. In the absence of

guidance she connected with, Patricia described referring back to particular readings and attempting to literally act the metaphors she had read about:

"I remember once reading something that said 'meditation is the spaces between the words', so I would have this phrase 'meditation is the space between the words' going through my mind, and I would try and stick on the spaces between the words." (Patricia: 1884-1894)

Rather than helping her connect with what she now understands as meditation, Patricia described being confused by the metaphor. She explained that she found it took her away from the meditative process of focussing on her body and the present moment. Patricia described persevering with mindfulness and eventually finding teachers who communicated the process in language she connected with. From her position of hindsight, Patricia clearly stated that initially she did not understand what she was trying to do. She was stuck trying to do something, but unsure what this was. It seemed that Patricia understood the instructions she was or was not given as the gatekeeper to conducting mindfulness properly:

"I'd be doing what they said, but it didn't, they didn't give me instructions that made that shift for me." (Patricia: 1585-1590)

Caroline spoke about a lady on her course who seemed to have a similar experience. The instruction of "bring [your mind] back" when it wandered was insufficient for her to understand how to carry out the process:

"There was a lady just to my right [] she didn't understand certain elements of this, you know when your mind drifts just bring it back, well how do I just bring it back? I don't know how to bring it back." (Caroline: 240-245)

It seemed that similar to Harriet and Patricia, this lady needed more. She appeared to require some explanation of what the bringing back process looked like. Indeed, Patricia explained that once she learned being mindful could mean focussing on one's breath in one's stomach, her understanding of the mindfulness process started to fall into place.

#### **4. Discussion**

The above findings illustrate some of the barriers that participants reported experiencing in relation to their MBIs. In particular, data highlights what these barriers were, the impact barriers had on engagement, and the emotions experienced by participants in light of such barriers.

##### ***4.1 Consideration of the current findings***

As described above, participants reported doubts both before and during the course about whether techniques would “work”. Such doubts appear espoused by participants in other studies too. For example, 21% of participants in Sears, Kraus, Carlough and Treat (2011) reported doubting whether meditation really worked. ‘Working’ appeared to hold a different quality for participants in Sears et al. (2011) to what individuals in the current study conceptualised it to be. Meditation seemed expected by participants in Sears et al. (2011) to ‘transform’ them, to make them happy, and to make them whole. For the current participants, ‘working’ seemed to fall into two camps – the management of emotions and, most prominently, the management (often reduction) of symptoms.

For Lucy, such doubts meant she almost decided not to attend the course. Caroline's account was similar, explaining that she would have “dropped out” and “dismissed mindfulness altogether” had she not believed it could help her (line 635/line 628). Sears and Stanton (2001, as cited in Sears et al., 2011) reported concordant findings. They found ‘expectancy violations’, whereby intervention was

not seen to match up to expectations, to be a predictor of dropout in an exercise programme. Similar findings exist within the psychotherapy research, suggesting that the more hopeful a person is, the better their outcome is likely to be (Irving et al., 2004). Sears et al. (2011) suggest that meditation instructors might want to reduce the chance of expectancy violations by explaining what can be more realistically anticipated from the process. The current researcher would argue the same.

Moreover, there may be utility in encouraging individuals to look past whether mindfulness ‘works’ and to the other benefits it can bring. Participants in the current study described finding mindfulness particularly helpful for emotion regulation, self-reflection, self-acceptance, and capitalising on what life has to offer. In some contexts, such benefits appeared to be experienced separately from the reduction of symptoms. These findings are consistent with those reported in Poppe et al. (2013). Poppe et al. (2013) found acceptance of life with ME/CFS and its subsequent limitations to be related to increased emotional stability and less psychological distress, beyond the effects of fatigue severity. Perhaps working to expand individuals’ perceptions of what ‘working’ means might lead to increased engagement and more widespread gains.

Expectancy violations also appeared present in the current study in terms of the actual mindfulness techniques. Irv described the techniques as too simple and Harriet explained she had tried them before, perceiving them as “relaxation” (e.g. line 1131). As described above, Irv found utility in the techniques months after the course as he realised “it’s simplicity that is the key” (300-301), whereas Harriet continued to perceive mindfulness as “another name for my relaxation tape that I’ve had since about 1985” (1167-1169) at the time of interview. Although both participants continued to practise the techniques throughout the course, it seemed their hope for a beneficial outcome had reduced. Again, perhaps pre-empting such

conceptualisations may reduce expectancy violation, maintain or increase hope, and help clients gain more from the intervention. In particular, facilitators might explain that at first techniques can appear simple and similar to others that individuals may have already tried.

Not only might managing expectations help improve outcome but it could also work to reduce the emotional distress caused when expectations are unmet and hope depleted. As explained earlier, Harriet described much disappointment and anger when recognising the techniques as relaxation. Irv talked about feeling resentful at the perceived simplicity of the techniques. Perhaps conceptualising mindfulness as relaxation may be a particularly likely occurrence for people with ME/CFS due to the frequency this population are thought to engage with it. Relaxation techniques, “i.e. guided visualisation or breathing techniques”, are recommended by the NICE guidelines for the diagnosis and management of ME/CFS (National Institute for Health and Clinical Excellence [NICE], 2007, p. 20). Similarly, 53.7 percent of 1,675 respondents to a survey carried out by the MEA (2010) reported ‘meditation or relaxation techniques’ to improve symptoms. This suggests at least 1,675 out of 3,663 respondents (just under half) were likely to have tried some sort of relaxation. Managing such expectations may therefore be a particularly important step when delivering MBIs to the ME/CFS population.

As described above, the current study highlighted other assumptions about MBIs and mindfulness that also appeared to create distress. For Harriet and Richard, scepticism was considered to be part of their identities. Both appeared to experience frustration for holding a sceptical attitude. They appeared frustrated because each seemed to assume that, should they be able to ‘give themselves’ to mindfulness, it would improve their symptoms. Irving et al. (2014) took a grounded theory approach to exploring a modified version of MBSR. They reported that irritation (as well as other difficult experiences) was “mitigated through group

dialogues in which experiences were normalized by instructors and other participants” (p. 65). Perhaps participants would benefit from facilitators anticipating and normalising scepticism. Explaining that people can still benefit from MBIs even though they feel sceptical about them may help to reduce distress, increase hope, and ultimately improve outcome.

As espoused in the current study, another potential barrier to outcome reported by participants was religion. Participants in Morgan, Simpson and Smith (2014) spoke about religion too. Similarly to Daniel, it seemed that some of these individuals experienced initial scepticism related to whether meditation would clash with their existing beliefs. Again, consistent with Daniel, these participants appeared to report positive experiences when this was found not to be the case. As described above, Harriet espoused a different experience. She talked about wondering whether her facilitator was “bringing a sort of faith thing into it” (2281-2282), which resulted in her feeling uncomfortable and being distracted from practice.

It could be argued that best practice would be to keep religion completely separate from MBIs. This would likely avoid religion-related resistance and disengagement. However, there appears to be a substantial body of research which suggests that the outcome of psychotherapy for religious individuals can be enhanced by incorporating religious elements into treatment (see Hefti, 2011). The account of Nadia, another of the current participants, appears consistent with this. Nadia talked about liking mindfulness especially because it fitted well with her religious beliefs. For Nadia, mindfulness was a way of fulfilling her spiritual potential. She said, “I’m quite a spiritual person so [] coming back to the truth and how you really are and being honest about that, erm, resonates with me” (333-338). She also said, “I feel like I have [] a true destiny, or I want to be the best I can be, and I feel that in order to do that it involves a lot of self-development, self-analysis, and meditation” (345-352). Nadia’s account appears consistent with findings from Morgan et al. (2014) in

which participants spoke positively about mindfulness training integrating well with their religious or spiritual beliefs. Rather than ignoring religion in MBIs, perhaps it may be more helpful if it was incorporated into the process when necessary. For example, facilitators could spend time with religious or spiritual individuals discussing how mindfulness could be integrated within their own practices and belief systems.

Finally, participants in the current study spoke about the importance of guidance. In particular, it seemed that guidance was the gatekeeper to making “that shift” from instruction to action (Patricia: line 1589). Other research has reported similar findings. For example, nine out of 10 ‘client’ participants in van Aalderen, Breukers, Reuzel, and Speckens (2014) considered it crucial for facilitators to meditate themselves so that they “know what is going on when meditating” (p. 172). A similar opinion appeared espoused by ‘facilitator’ participants. They said that teachers needed to be able to give examples from their own life so clients too could understand how to integrate mindfulness into their lives. Perhaps ensuring facilitators are experienced in using mindfulness to manage their own difficulties is an important step for MBI organisers.

#### ***4.2 Limitations of the current study and suggestions for future research***

Overall, the current research methodology achieved what was hoped. It allowed the researcher to illuminate the phenomenon of engaging in MBIs whilst living with ME/CFS. As with all research, the process has not been flawless.

As mentioned in the Methodology, individuals who had experienced MBIs for less than six weeks were excluded. This was considered a positive and necessary step to ensure that participants had enough experience from which to provide detailed data about their interventions. However, this requirement possibly meant the individuals interviewed were all relatively committed to their MBIs. Even Harriet,

who remained sceptical about the utility of mindfulness, reported that she attended all sessions and completed all the homework. It could be that richer data regarding negative experiences of MBIs and barriers to engagement would have been gathered from individuals who had attended fewer sessions. Since barriers appear so important to outcome, perhaps future research could focus on experiences of those who dropped out of courses early.

Also mentioned in the Methodology was the requirement of participants to meet the Fukuda et al. (1994) criteria for ME/CFS. As explained in the Introduction, a growing body of research suggests that 'ME/CFS' may be an umbrella term which encapsulates different symptom clusters, aetiologies, and severities (e.g. Brown et al., 2013; Jason et al., 2012; Sullivan et al., 2005; and Jason et al., 2004). This questions the validity of the Fukuda et al. (1994) criteria, suggesting it may cluster different subsets of individuals under one overarching label. If this is the case, it might mean that comparing samples selected via the Fukuda et al. (1994) criteria is a questionable endeavour. However, it could be argued that such comparison is only problematic in larger studies seeking to generalise findings. Additionally, IPA prioritises experience, not correlates of diagnosis, at the forefront of investigation. IPA studies seek to compare experiences not diagnoses. Thus, the question of whether the current sample was made up of different subsets holds less importance than one might initially imagine. For further clarity, perhaps future researchers might seek to elucidate which subset their participants could be classified within.

Further noted in the Methodology was the debate around 'ethics of interpretation'. Researchers such as Willig (2012; 2013), Kvale (as cited in Willig, 2012), and Latour (as cited in Willig, 2012) argue that it is important for participants to have the opportunity to object to what is said about them. This may be particularly important in the area of ME/CFS, as historically a rift appears to exist between particular research findings and some individuals and groups with ME/CFS (see The MEA,

2007; Moss-Morris & Petrie, 2000). This rift could mean that individuals are restricted from accessing treatment options which could be helpful. In light of the above, perhaps the current study would have been more ethical had the researcher engaged in 'member checking' whereby interpretations are taken back to participants and amended as applicable. Not only might this have ensured that participants' experiences were less likely to be misrepresented, but it may also have communicated that psychologists are willing to listen and desire to give people with ME/CFS a voice. Unfortunately, member checking was difficult due to the limited amount of time for this research. However, this author would advocate member checking whenever possible in research conducted within the ME/CFS field.

In conclusion, the theme 'Struggling with doubts and understanding' was extracted in the researcher's doctoral thesis and thought useful for dissemination. Findings suggest that facilitators may do well to recognise the expectations of clients with the aim of managing 'expectancy violation', reduce potential distress, and maintain hope for beneficial outcomes. Facilitators may pre-empt assumptions about techniques 'working', what 'working' means, the appearance of techniques, and thoughts about scepticism. Perhaps best practice would mean considering mindfulness in light of individuals' religious beliefs. Also, facilitators holding personal experience of using mindfulness constructively may be crucial to client outcome. The current study can be critiqued regarding sampling and ethical considerations. Nevertheless, it has certainly provided some interesting and useful data as well as avenues for further investigation.

## **5. Acknowledgements**

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## **6. Ethical standards**

The study was approved by the ethics committee at City University London and has therefore been conducted in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. Research was also carried out in reference to the British Psychological Society's Code of Human Research Ethics (2010). No participants were interviewed who reported current or recent beliefs that life is not worth living or that they would be better off hurting themselves in some way. All persons were clearly informed as to the aims of the study and potential risks of participation. All gave their informed consent to participate prior to inclusion in the study.

Activity was monitored and staggered to reduce the chance that participants' symptoms would be exacerbated during the process.

## **8. Conflict of interest**

The author declares that she has no conflict of interest.

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## **Part three – Client study**

### ***A gentleman experiencing Parkinson's disease: Working from an integrative model with Ray***

#### **1. Introduction and the start of therapy**

##### ***1.1 Introduction/rationale for the choice of case***

There is a substantial body of research which finds the quality of the relationships between therapists and clients to consistently predict therapeutic outcomes, regardless of the model being used or the presenting problem (Pilgrim, Rogers & Bentall, 2009). As frequently espoused by my tutors, who dedicated much of their time to preparing my cohort for the job market, we need to be able to justify to an organisation why we, with our expensive salaries, should be employed instead of lesser trained and less expensive others. If it is all about the relationship, what expertise do we have that others do not, and outside of the relationship, what more do we have to offer?

Ray<sup>13</sup> and I worked together during the third of my four years in doctoral training. His case has been chosen for presentation because it is thought to showcase the strengths of the psychologist well. First, it demonstrates our ability to work pluralistically. Pluralism is a philosophical stance which advocates that no superior overall truth exists. As explained by McAteer (2010), pluralistic practitioners recognise the validity of numerous competing perspectives and therefore work flexibly, moulding their approach to the client in-front of them. Second, it is hoped that the study illustrates the psychologist's expertise in building client-therapist relationships. Third, it is hoped that the account demonstrates the psychologist's proficiency in using this relationship to effect change. Fourth, it shows our

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<sup>13</sup> All names and identifying features have been changed.

awareness of context and the psychologist's ability to navigate this influence in the therapy room. Fifth, the study illustrates how we use research to inform our practice.

A substantial amount of literature reports a link between Parkinson's disease and low mood (Jones, Pohar & Patten, 2009). A study by Loftus, Davies, Thornton and Turnbull (2009) suggests that in a fifth of individuals with Parkinson's disease low mood is associated with receiving care from spouses. This certainly appeared to be the case for Ray. As well as to demonstrate the strengths of the psychologist, Ray's case was also chosen to illustrate the experience of an individual with Parkinson's disease. It was hoped that in doing so this would provide readers with an insight into such an experience and how this might present in therapeutic practice.

In this paper I talk about how I fought to navigate the medical discourse and struggled with my self-confidence as a practitioner. I anticipate that others face similar difficulties and therefore another reason for presenting this case is to discuss difficult issues thought to be relevant to other practitioners.

### ***1.2 The theoretical model***

Consistent with McAteer (2010), I consider myself to be a pluralistic practitioner. In practice, this means I choose the model I use depending on the client in-front of me, what I know about my own belief system and the stories told by research literature.

The choice was made to work integratively with Ray, incorporating psychodynamic concepts into a person-centred foundation. To illuminate my rationale I shall explain what each have to offer and why these elements were important. The person-centred model was proposed by Carl Rogers (see Rogers, 1957) and belongs to a therapeutic paradigm called Humanism. It offered a model of working that was consistent with my personal belief system. I believe that humans best develop in a safe space, where they can explore themselves without criticism. I trust each

person is innately wise and given the right conditions will search for and find their own answers. I value honesty and believe that being honest shows respect for another person. Similarly, the person-centred model suggests that adhering to six core conditions creates a respectful space in which a person can connect with their inner wisdom and move towards change. Rogers' core conditions can be summarised as follows: one individual (the therapist) spends time with another individual (the client) and achieves to a minimal extent the experiencing and communication of unconditional positive regard and empathic understanding. The client must be in a state of incongruence and the therapist congruent within the relationship.

A study by Luborsky et al. (1999) provides compelling evidence for the argument that therapists should work in a manner consistent with their personal belief system. Luborsky et al. (1999) investigated the relationship between researchers' allegiances to treatment and the outcome of that treatment for clients. They found that 69% of variance in client outcome could be attributed to the researcher's allegiance. The study strongly suggests that therapy is likely to be more beneficial if the therapist believes in the approach they are taking. Although my philosophy is complemented well by the Rogerian model, in contrast to Rogers, I do not believe the six conditions are sufficient to elicit change in all individuals. In practice therefore, when developing the model for Ray, I started with a person-centred foundation and incorporated, within the limits of my knowledge, what I believed we needed to effect change. My method was supported by Horton (2010), who suggests that a coherent integrative model depends on it being consistent with the therapist's philosophy.

The psychodynamic concepts of the unconscious, transference, countertransference, defences and interpretation can be traced back to Sigmund Freud, commonly accredited as the founding father of the psychodynamic

approach. These concepts are explained fully by Jacobs (2010). Transference is the name given to the phenomenon whereby person A's presence effects the experience of person B without either person being initially conscious of the process. Countertransference is a similar phenomenon but refers to the effects person A experiences as a result of person B's unconscious response to them. The term 'defence' refers to action taken by an individual to cope with unconscious anxieties, preventing these anxieties from presenting in the conscious. Making an interpretation means communicating the therapist's understanding of what is happening and why this is happening to the client. The psychodynamic approach affords the therapist an expert status (Jacobs, 2010).

I decided these psychodynamic concepts were important to incorporate into my work with Ray because of his presentation in our initial session. First, Ray said he hoped I could work a miracle and explained he was desperate. At the time I was quick to label myself a "rubbish" therapist and afforded myself a heightened amount of responsibility for client outcome. It was reasonable to assume that Ray's expectations would touch on my vulnerabilities and hence the process of therapy. Second, Ray articulated strong beliefs regarding men and women and the problems he described centred on the theme of aging. Again it was reasonable to anticipate that my status as a young female would influence how both Ray and I presented in sessions. Third, Ray often did not answer my questions directly and moved from topic to topic in a way I found confusing. I had previously worked using a person-centred model with a client who presented in a similar way and I found that the conversation stayed at surface level with little change being achieved. Fourth, Ray expressed wanting to work towards a goal I felt likely to be unrealistic.

I therefore wanted an approach that would allow me to be particularly aware of the impact Ray's expectations and beliefs had on my interventions, and of the influence my youth and femininity had upon Ray's presentation. I decided to make use of

transference and countertransference as they allow the therapist to explore the effect of one person on another in depth. I also wanted a model that could recognise Ray's tendency to not give direct answers and to talk in a confusing manner as a phenomenon, as well as one that would give me a reason for why this behaviour occurred, and afford me a 'tool' I could use to work with it. I decided thus to incorporate the concept of defences and the act of interpretation. I also desired an approach that would allow me to take an expert status if needed. Consequently, my model consisted of a Rogerian foundation integrated with the psychodynamic concepts of transference, countertransference, defences, interpretation and therapist expertise.

Consistent with the advice of Jacobs (2010), I tested the use of interpretation in our initial session. Ray responded well by considering my hypotheses and building upon these. Jacobs (2010) argues that such a response suggests that the psychodynamic focus is suitable for a client.

### ***1.3 The therapeutic context and referral***

Manafi (2010) holds that the context we work within impacts the therapeutic process. She argues that each individual views the world through a particular lens and thus their understanding is shaped by elements such as power, economy and politics. The following information is therefore included to illuminate the possible factors shaping my lens during therapy with Ray.

At the time I was nearing the end of a placement in a hospital outpatient department. The current waiting time was 10 months and therapy was restricted to 10 sessions. Referrals came through the medical system and a medical discourse was dominant.

Ray was referred by his physiotherapist who wrote that his anxiety was affecting his walking. The letter was worded in a manner which suggested this would be the

focus of our work. At the time of our first appointment Ray and the physiotherapist were coming to the end of their work together. The letter noted that Ray had a diagnosis of Parkinson's disease.

#### ***1.4 Convening the first session***

Ray attended the first session with his daughter and expressed a wish for her to stay in the room throughout appointments. I explained that it is common practice not to allow anybody other than the therapist and client in the therapeutic space and outlined the rationale behind this. This was followed by me describing the limits of confidentiality then proceeding to ask Ray why he had come to therapy.

#### ***1.5 Our understanding of the problem and my initial formulation***

Ray explained that he had come to increase his physical mobility. He described being unable to keep his balance whilst walking without holding an aid. His difficulties had started two years previously when he had fallen a number of times whilst playing bowls. Ray explained that he felt low in mood much of the time and attributed his low mood to being unable to play bowls and his growing dependence on his family. Ray described himself as stuck, not knowing how to regain his mobility as it once was. His hope was that I would get him back to mobilising as he did before his falls.

I found it helpful to conceptualise Ray's problem in terms of what was stopping him from moving forward. First, Ray did not have a clear idea of the extent to which his physical difficulties were reversible. He was avoiding finding this out. This avoidance was problematic as I was unaware of how realistic his goal was. Second, Ray appeared to be holding onto an identity in which mobility problems were not acceptable. This was problematic because he seemed to be denying the probable reality of his situation - that it was unlikely he could regain full mobility and sustain this for the rest of his life - and in doing so, hindering movement towards

acceptance. Acceptance of an illness has been found to coincide with positive mental attitude and quality of life scores in individuals aged 60+ (Kurpas, Mroczek & Beilska, 2013).

Ray described himself as a “man’s man”. The first time he said this I noticed that he sat up in his chair and opened his chest. He communicated this understanding of himself with pride. I hypothesised that perceiving himself in this way afforded Ray a sense of personal worth. In their guide to person-centred counselling Mearns and Thorne (2007) explain that if a person understands their worth as dependent on certain conditions then they are likely to experience emotional difficulties when/if a situation arises whereby they cannot uphold these. My understanding of a man’s man is of a strong, virile and independent individual. I hypothesised that when Ray developed mobility problems he no longer understood himself as such. I guessed that this left him lacking in a sense of personal worth and therefore low in mood. Mearns and Thorne (2007) highlight that individuals develop self-concepts dependent on fulfilling conditions because of experiences with critical or punitive others. Consistent with this theory, I learned in later sessions that Ray’s father had been punitive and would frequently hit him to ensure obedience.

I hypothesised that Ray’s use of the denial mechanism allowed him to maintain some semblance of the man’s man self-concept. It seemed Ray was protecting himself by avoiding seeking or acknowledging information which could undermine this identity. I guessed that not allowing himself to consider life as a disabled man kept Ray in a state of incongruence; not fulfilling the role of a man’s man yet discontent in not doing so. This use of denial seemed to prevent Ray from incorporating the realities of his situation into a congruent and desirable self-concept.

In our first session I noticed myself feeling confident and competent. Usually I would have experienced anxiety when unaware of the extent that biological factors were affecting a client's symptoms. The absence of anxiety that I felt suggested a splitting and suppression of anxious feelings. It may have also indicated that I was introjecting Ray's fantasy that I had the knowledge to reverse his symptoms. I guessed I was employing defences in response to the fear that I might not be able to help Ray achieve his goal. Ray said he trusted me 100% and had faith I could work a miracle. Ray's unfounded declaration of trust and his unrealistic hopes were suggestive of idealisation, a defence employed to hide negative feelings towards a person from the conscious. I guessed that Ray was trying not to acknowledge that I might not be able to improve his mobility. This seemed preceded by the fear he might never get his mobility back. I was able to theorize then that both Ray and I were feeling anxious about the outcome of therapy.

### ***1.6 Negotiating a contract and therapeutic aims***

Consistent with the limits of the service I offered Ray 10 sessions. If my hypothesis was correct and Ray conceptualised any persona other than the man's man as worthless, this pattern would likely have been present for over 60 years. I anticipated that if Ray's symptoms were irreversible it would take him longer than 10 sessions to integrate having mobility problems into a self-concept he was content with. I felt Ray would benefit from longer term therapy. To this end I suggested incorporating a review into session eight where we could talk about Ray's options and plan for the final two appointments.

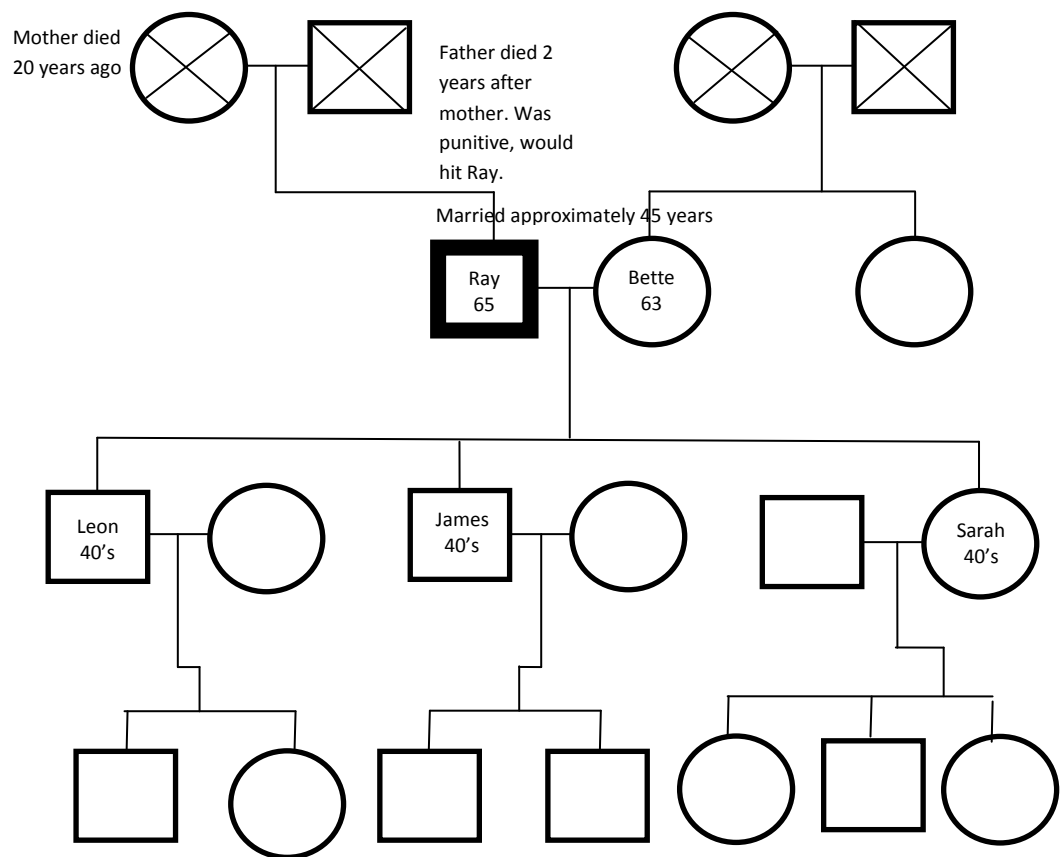
Ray and I discussed therapeutic goals at length in our first two sessions. During this time it became clear that, certainly on an unconscious level, Ray did not want to know whether returning to his previous mobility was a realistic option. Moreover, even if this was realistic in the short-term, Parkinson's is a degenerative disease and Ray would be likely to face mobility difficulties in the future. Obviously it would

have been unethical to work towards a potentially unrealistic goal and/or leave Ray vulnerable for the future. If Ray had indeed conceptualised any persona other than the man's man as worthless for over 60 years, it would also have been unrealistic to set goals around acceptance. Instead of setting clear goals therefore, I suggested a focus for the work; exploring Ray's mobility difficulties and what these might mean. A clear focus is understood as sufficient for short term work in both person-centred and psychodynamic models (Bravesmith, 2010; Mearns & Thorne, 2007).

### ***1.7 Biographical details and the genogram***

Ray was a 65 year old Caucasian male. His parents had died over twenty years earlier and he was an only child. Ray had worked all his life as a carpenter, retiring five years previously. Ray lived with his wife Bette. They married in Ray's early twenties and Ray described her as a "very strong character". Ray and Bette had three children who each had children of their own. Ray received a diagnosis of Parkinson's disease about 18 months before we met. Refer to Figure 1, Ray's Genogram.

Figure 1: Ray's genogram.



## 2. The development of the therapy

### 2.1 The pattern of therapy

Ray did not pay directly for his therapy as it was provided through the NHS. We met weekly for 10 50 minute appointments. Ray and I missed two of our sessions; once due to illness on my part and once because Ray forgot. Ray rang the service twice to apologise and ensure we would book another session. He appeared committed to and engaged with the therapy. Ray arrived on time for all his sessions and, except for our initial appointment, came alone. He showed good eye contact and made an obvious effort to participate in the sessions.

## ***2.2 The therapeutic plan and the main techniques used***

The philosophies and concepts described in the therapeutic model informed a series of actions which I outline here as ‘techniques’. To generate a state of congruence within myself I focus on bodily sensations then search for a word which best describes them. Some authors may recognise this as ‘focussing’, a technique discovered by Eugene Gendlin (e.g. Gendlin, 2003) and consistent with the humanistic school. To experience empathy I make use of ‘touchstones’, personal memories which embody for me the experience of particular feelings. Touchstones allowed me to imagine how I have previously felt when experiencing the feelings Ray talked about. I found it easy to experience positive regard for Ray as there were many things I liked and admired about him. I used both words and gestures to communicate the above to him. This use of gesture to communicate is supported by neuropsychological literature which has found that humans dedicate a large portion of the brain to encoding and decoding non-verbal signals (see Schore, 2010).

Consistent with many in the psychodynamic tradition, I make interpretations based around Malan’s triangles. These triangles are a diagrammatic representation of relationships between the client, the therapist, significant others, unconscious anxiety and early experiences (see Malan, 1979). Similar to my use of congruence, my use of transference and countertransference involves focussing on my present experience. The latter concepts allowed me to then generate hypotheses about why I might be experiencing what I was in my encounters with Ray. This process is conceptualised by the therapist Patrick Casement as trial identification (see Casement, 1991).

In light of the techniques I intended to use and the therapeutic focus, my plan was as follows:

- a) Provide a space in which Ray could learn to trust me. Laughton-Brown (2010) suggests that trust-building is particularly important at the beginning of therapy as it allows the client to express their emotions.
- b) Provide a space in which Ray could reflect and establish contact with his inner experiences.
- c) Provide a space where the feelings he was defending against could be safely acknowledged and explored.

If Ray and I achieved the above I planned to provide an atmosphere in which Ray could begin to tentatively establish a less fragile sense of worth. If we had more time together my aim would have been to help Ray incorporate being a man with mobility problems into a congruent and acceptable self-concept.

### ***2.3 Key content issues, the therapeutic process and changes in the therapeutic process over time***

#### **2.3.1 Ray's progression**

The beginning of our work focussed much around Ray's expectations. Although I explained in our first session that to work on his mobility Ray would need to find out the extent to which his problems had a biological aetiology, he came to our second session having made no plans to find this out. Casement (1991) suggests that when a client agrees verbally to what the therapist communicates yet no significant shift occurs, the client can be understood as experiencing unconscious resistance. In light of this, I hypothesised that Ray was using the denial mechanism.

The focus of the work then moved from Ray's expectations to his defences and the identification and exploration of these. Partway through the second session I noticed an anxious feeling in my stomach. As I focussed on this I realised it was because Ray had not used the words "Parkinson's disease" once throughout our

sessions. Was the referral letter wrong? Was Ray unaware of his diagnosis? I asked Ray whether he had Parkinson's disease and he answered "yes". Referring to my hypothesis from the previous session, I concluded that not using the words Parkinson's disease was another manifestation of denial. I thus offered Ray an interpretation – perhaps he was avoiding using the words and asking the biology question because it was too scary to consider that he might never regain his mobility. Ray agreed.

In the next part of our work we focussed on the realities of Ray's situation. I could see that something had changed for Ray because where, in our earlier sessions, Ray expressed much hope that a cure would be found, he was now considering the reality of this happening. Ray acknowledged that his physiotherapist felt he had reached his potential. At this point Ray began talking about booking a holiday. It was the first time he had talked about the future. It appeared Ray was permitting himself to be a man with mobility problems in the future. Perhaps Ray's understanding of his self-worth as a physically-limited man had changed a little.

A few sessions later Ray arrived very distressed. He reported having problems with his memory. I was surprised that Ray was so distressed because he had talked about having memory problems ever since we began our sessions. I hypothesised that, as with the probable permanence of his mobility problems, Ray had not previously allowed himself to acknowledge that he had memory difficulties. I took Ray's acknowledgment of these issues to indicate that their presence was less anxiety provoking than it had been previously.

The latter part of the work focussed around looking toward the future. Ray arrived to our next session having told his family about his memory difficulties and having passed on the bookkeeping for the family finances to his children. Although Ray was experiencing sadness he was also experiencing some kind of acceptance. The

last time I saw Ray he had booked a holiday. He was acknowledging that the future was going to happen and was taking control of it.

### **2.3.2 The development of our relationship**

In our initial session Ray indicated that he did not trust me. He wanted his daughter in the room with us and made use of idealisation, a defence employed to hide negative feelings about another. Consistent with the Rogerian stance on building therapeutic relationships, I worked hard to treat Ray with kindness, compassion and empathy. This was difficult at times as I did not want to upset him or make him angry with my honest opinions.

Over the next few sessions Ray began to trust me with a little personal information. He told me about Bette becoming frustrated towards him and described feeling angry with her. He did not elaborate on this when asked. Consistent with the person-centred philosophy, I did not push Ray to tell more. I wanted to keep the space safe for him and I trusted he would elaborate when it was right for him to do so. Instead I took the opportunity to create a genogram (see Figure 1). I hoped that by doing so I would learn more about the dynamics between Ray and his family and the context which Ray was coming from. I also hoped that by creating a genogram Ray would start to acclimatise to talking about his family in the therapy room and feel more able to do this in future.

In the following sessions Ray told me a lot more about what he and Bette argued about. Contrary to his belief that a man should never swear in-front of a lady, he swore. Ray said he was telling me things he had never told anyone else. I understood Ray's behaviour to indicate that he trusted me more than before. He knew I would not judge him, and appeared to regard me differently to the stereotypical woman who must not be subjected to swearing.

A few sessions later, Ray asked me, with an air of incredulity, whether I could understand what things were like for him because I had never been in the same situation. Rogers (1967) encourages the therapist to show the client a real person, what the therapist is and what the therapist feels are good enough. With this in mind I explained that although I have never been through what he has, I have felt the same emotions that he expresses, hence can guess relatively accurately what his experience must be like. This discussion set the stage for what felt like the most poignant moment in the therapy. Later that session I began to feel a hollowness in my stomach and recognised it as loneliness. I wondered whether I was experiencing a phenomenon that Casement (1991) writes about - when the feelings one person has are so strong they spill out into others. I took a risk and said "it must be really lonely where you are". Ray looked me straight in the eye and his chin began to quiver. His voice cracked and he said "it's hell". In this moment I felt a sense of deep connection with him. It appears Ray felt it too as he said afterwards he felt very connected with me. From then on Ray talked openly about feelings which could have been considered "unmanly" such as embarrassment, uselessness and weakness. Our relationship remained strong.

#### ***2.4 Difficulties in the work***

I found it very challenging to settle on a focus for the work. Ray and I had two choices - increasing his mobility or developing a self-concept no longer dependent on full mobility. I found that my thinking had been influenced greatly by the medical discourse and the referral letter. In a report published by the United Kingdom Council for Psychotherapy (UKCP) which scrutinises the development of the NICE guidelines, Guy, Thomas, Stephenson and Loewenthal (2011) argue that the medical model conceptualises therapy as the equivalent of a pill. According to the medical model, therapy is about the therapist doing something to the client to elicit a predetermined outcome. This assumption was certainly evident in the referral letter.

The conventions of the medical model interacted strongly with my personal vulnerabilities. A voice in my head told me it was my job to 'cure' Ray. It said I had violated my job description when I chose not to follow the assumed path the referral letter described. The voice said that when Ray did not find out about the aetiology of his difficulties I should have written to his consultant so we could have continued along the expected path. For me, the medical discourse is a powerful other which elicits much anxiety when contravened.

I dealt with this anxiety by exploring other discourses. For example, I reminded myself that the UKCP (Guy et al., 2011) conceptualise therapy as a discourse and say the "therapy as pill" analogy is invalid and at times harmful. I engaged in discussions with peers and tutors who have also felt influenced by the medical discourse. They had chosen paths similar to mine and I drew strength from their anecdotes.

I also found working with Ray challenging because the realities of his case challenged my personal beliefs. In accordance with the person-centred model I generally hold that the client knows best. However, I could not ethically allow Ray to work towards what he wanted to. We did not know if his goal was realistic, and in working this way we would be ignoring the likely realities of the future. I felt I had to take the expert position. This elicited much anxiety for me; who gives me the power to say what is best for somebody? I faced a difficult choice - to undermine Ray's expertise and work realistically, or respect his expertise and work unrealistically.

I dealt with this by referring to my own moral compass and to the ethical guidelines written by the Health and Care Professions Council (2012) and the British Psychological Society (2009). I worked consistently with their literature; acting in the best interest of my client and exercising my own professional judgement.

## ***2.5 Use of supervision and liaison with other professionals***

### **2.5.1 One-to-one supervision**

I explored moments of disconnection in the therapy during supervision. My supervisor suggested that these moments often occurred for me when my clients and I had different understandings of the same situation. Due to this insight, when I noticed Ray had not used the words “Parkinson’s disease” I took action to establish whether our understandings were different. The information I gained allowed us to move forward. Without this insight the work may have moved slower.

My supervisor exhibited much confidence in me when I explained that I was working integratively and why. I was the only practitioner in the department who worked using integrative models. Again, breaking from the powerful other caused me anxiety; however my supervisor’s support gave me confidence and aided my development into a pluralistic practitioner.

### **2.5.2 Group supervision**

I presented Ray’s case in group supervision at university. It was the group who highlighted that even if Ray’s mobility improved in the short-term, it would likely degenerate as his Parkinson’s progressed. It was also this group who suggested that Ray’s unconscious communication indicated a lack of trust. Ray had said he trusted me and initially I did not question this. After the supervision I was better able to make an ethical decision regarding the focus of the work. I also saw our relationship more realistically and hence focussed on building this more than I might have without this insight.

### **2.5.3 The internal supervisor**

The internal supervisor is described by Casement (1991) as a space within the therapist whereby they generate insights about the process occurring in a session

at the time of the session. The concept of the internal supervisor allowed me to consider how different theories would explain what was happening in the therapy room. I frequently referred to my internal supervisor during my work with Ray. For example, where I used Casement's (1991) concept of trial identification to respond to the hollow feeling I recognised as loneliness.

#### **2.5.4 Informal peer supervision**

I discussed Ray's case with a peer from my course who is experienced in psychodynamic work. At the time I was focussing on mapping Ray's current presentation onto early developmental experiences. My peer encouraged me to focus less on this and more on the process evolving between myself and Ray. His advice helped me decide which psychodynamic concepts to include in my model.

#### ***2.6 Changes in the formulation and the therapeutic plan***

As Ray changed so did my formulation. When Ray's use of denial and idealisation diminished I reformulated to make sense of the present sessions. I noticed then that Ray talked only about the time from his first fall up until the present. He never talked about the past or future. I hypothesised that Ray was splitting his experience. As mentioned earlier, splitting is thought to occur when a person separates ambivalent feelings about the same person, phenomenon, or event (Jacobs, 2010). Individuals are then able to use the counterparts in different ways. In Ray's case, I hypothesised that he was suppressing his memories of the past and his visions for the future. Suppressing is another defence mechanism; here information is unexpressed yet not forgotten (Jacobs, 2010). Ray had told me that he felt like he was no longer the man he once was. I guessed that Ray might be using suppression because it was too anxiety-provoking to think about the man he used to be or the man he might become. As I hypothesised in my initial formulation, it appeared that when Ray lost his mobility he lost his sense of himself as a strong,

independent and virile man. I postulated that suppressing memories of the man he was pre-fall made it difficult for Ray to incorporate a sense of independence, strength and virility into his current self-concept.

In light of this I decided to make contact with the “pre-fall” Ray. To do this, I asked him to tell me about bowls. Ray was an expert on this subject. I hoped that speaking with confidence and passion as well as taking on the role of teacher would allow Ray to bring a sense of virility and authority into his present experience.

### **3. Conclusion of the therapy and the review**

#### ***3.1 The therapeutic ending and arrangements for follow up***

I hypothesised that the ending of therapy would be another loss for Ray. Not only would he lose me but he would lose once and for all the hope that he could regain his mobility through our sessions. In light of this I navigated the ending of our sessions very carefully.

It was made clear to Ray from the beginning that the ending of our sessions might not mean the achievement of his goals and that we would consider his options in a review session. Consistent with advice given in group supervision, each time Ray and I met I informed him of which session we were currently conducting and how many were left.

Ending was discussed specifically in the final two sessions, which were spread out. It was hoped that Ray would get used to not coming to therapy whilst still having the support of knowing he had appointments left.

#### ***3.2 Evaluation of the work***

Casement (1991) says that it is only by tolerating unknowing and being willing to wait that the therapist avoids imposing their agenda on the client. I felt greatly incompetent when I did not know whether Ray’s goal was realistic. I could have

written to his consultant or accessed his medical records to ease my own anxiety and pave a clear path down which the therapy could proceed. However, I strongly believed that Ray was not finding the information out for a reason and that this reason was an important part of Ray's experience. I congratulate myself for tolerating my anxiety. How damaging our work could have been had I assisted Ray in denying his symptoms and their potentially inevitable progression.

I also congratulate myself for allowing myself to be vulnerable with Ray. Often my hypotheses were generated through experiencing difficult emotions such as anxiety and confusion. Ray resonated with many of my hypotheses and I believe he benefitted from my insights.

When Ray said he did not know whether his goal was realistic I immediately encouraged him to find this out. Looking back I question whether this was a well-informed decision. Ray was obviously using defences for a reason. Had Ray seen his consultant or GP and found his symptoms were irreversible he could have reacted very badly. It may have been better to first establish therapy as a safe space and then help Ray develop other coping mechanisms before suggesting he seek medical opinion.

### ***3.3 What I learnt about psychotherapeutic practice and theory***

I learned through Ray's case that the models I choose to use with my clients may not be the best for them in all contexts. In accordance with Horton (2010), I created a model consistent with my philosophy. However, as noted above, my philosophy advocated taking action which might not have benefitted Ray and might even have been harmful to him. Before Ray's case I conceptualised stepping out of the model as undesirable and as indicating an incoherent practitioner. Upon reflection I realised that this is sometimes necessary and part of being a professional with professional judgement.

When Ray arrived at our initial session he came with the understanding that he could bring his daughter in with him. This understanding was based on a leaflet that the service sends to clients when they are originally referred. I was unaware of the contents of the leaflet and that it was being sent. The service and I therefore gave Ray mixed messages, which likely had some effect on how safe Ray initially felt the space to be. I have therefore learned to spend time familiarising myself with the admin processes of the service I am working in, and considering the impact they may have on the process inside the room.

Ray's case was the first where I engaged in group supervision from a psychodynamic approach. Presenting Ray's case, and engaging in the case presentations of others, taught me how to use my body to generate hypotheses about clients. I also learned new ways in which formulation can inform the work. An example of this was when my hypothesis about Ray suppressing memories of his past self led me to engage him in a discussion about bowls.

Ray's case also highlighted to me the utility of updating the formulation. Having a flexible formulation which evolved over time allowed me to move with Ray as he progressed. I was therefore able to make interventions relevant to where Ray was in the present moment.

### ***3.4 Learning from the case about myself as a therapist***

Even now I question my competence as a practitioner. Obviously, it is ethical to question one's work. Lack of questioning could easily lead to unethical and stagnated practice. As I question my work, however, my critical voice often tells me I am not good enough; I should be doing better. Whilst reflecting on Ray's case, I learned that I frequently understood feeling anxious as an indication I was working poorly. Not only did I gain this insight but I began to challenge the reality of this assumption. I felt incredibly anxious about my work with Ray, however, as I

considered the choices I made and the movement Ray experienced, I can see that I worked bravely, ethically, and competently. When working with clients post-Ray, I have questioned more vehemently the assumption that feeling anxious means I am working incompetently.

At the time of working with Ray I was 25 and thus relatively young to be in the third year of doctoral training. Occasionally my age leads some clients to question my competence. My work with Ray highlighted to me that it was not only clients who made such assumptions, but that I too made them. A year later I can say that this learning has stayed with me and that age is much less of an issue from my side of the encounter.

My time with Ray allowed me to draw conclusions about my future career. First, the anxiety I experienced in navigating the medical discourse, although not unique to my work with Ray, was certainly highlighted by his case. I postulated that I may gain greater job satisfaction if working in a context where the medical discourse is less prominent. Second, both Ray and I would have liked more sessions if the choice was available. It was difficult for me to end knowing that given the choice both Ray and I would have continued. I also postulated that I might gain greater satisfaction in a service with the potential for longer-term work.

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## **Appendices**

### **Preface**

Appendix A: Submission requirements for 'Mindfulness' (shortened)\*

### **Part One – Doctoral research**

Appendix B: Excerpt of transcript analysed from emergent themes

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### **Part Two – Publishable piece**

Appendix P: Question Schedule

***Appendix A: Submission requirements for 'Mindfulness' (shortened)\****

\* Guidelines have been shortened for the purpose of this portfolio and only the information thought relevant to the writing of the piece included here.

### **Aims and scope**

*Mindfulness* seeks to advance research, clinical practice, and theory on mindfulness. It is interested in manuscripts from diverse viewpoints, including psychology, psychiatry, medicine, neurobiology, psychoneuroendocrinology, cognitive, behavioral, cultural, philosophy, spirituality, and wisdom traditions. *Mindfulness* encourages research submissions on the reliability and validity of assessment of mindfulness; clinical uses of mindfulness in psychological distress, psychiatric disorders, and medical conditions; alleviation of personal and societal suffering; the nature and foundations of mindfulness; mechanisms of action; and the use of mindfulness across cultures. The journal also seeks to promote the use of mindfulness by publishing scholarly papers on the training of clinicians, institutional staff, teachers, parents, and industry personnel in mindful provision of services.

### **Instructions for authors**

#### ***Abstract***

Please provide an abstract of 150 to 250 words. The abstract should not contain any undefined abbreviations or unspecified references.

#### ***Keywords***

Please provide four to six keywords which can be used for indexing purposes.

#### ***Text formatting***

- The text of a research paper should be divided into Introduction, Materials and Methods, Results, Discussion, Acknowledgements, Conflict of Interest, and References.
- Materials and Methods must include a statement of Human and Animal Rights.
- Use italics for emphasis

#### ***Headings***

Please use no more than three levels of displayed headings.

#### ***Abbreviations***

Abbreviations should be defined at first mention and used consistently thereafter.

#### ***Footnotes***

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively. Always use footnotes instead of endnotes.

### ***Acknowledgements***

Acknowledgments of people, grants, funds, etc. should be placed in a separate section before the reference list. The names of funding organizations should be written in full.

### ***Citation***

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott 1991; Barakat et al. 1995; Kelso and Smith 1998; Medvec et al. 1999).

### ***Reference list***

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be italicized.

### ***Article length***

The average article length is approximately 30 manuscript pages.

### ***Ethical standards***

Manuscripts submitted for publication must contain a statement to the effect that all human and animal studies have been approved by the appropriate ethics

committee and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

It should also be stated clearly in the text that all persons gave their informed consent prior to their inclusion in the study. Details that might disclose the identity of the subjects under study should be omitted.

These statements should be added in a separate section before the reference list. If these statements are not applicable, authors should state: The manuscript does not contain clinical studies or patient data.

### ***Conflict of Interest***

Authors must indicate whether or not they have a financial relationship with the organization that sponsored the research. This note should be added in a separate section before the reference list.

If no conflict exists, authors should state: The authors declare that they have no conflict of interest.

***Appendix B: Excerpt of transcript analysed for emergent themes***

## Appendix B: Excerpt of transcript analysed for emergent themes

|                                              |                                                                                                |                                                                                                                                                                                                                       |
|----------------------------------------------|------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Awareness of course during energy management | H: Well it's on ah on a you                                                                    |                                                                                                                                                                                                                       |
|                                              | know on a practical level                                                                      | <b>Practical level.</b> Seems a consideration of practical issues. What practical issues does she have to consider?                                                                                                   |
|                                              | when you're trying to pace                                                                     | <b>Attempting to pace.</b> Talking about energy management here.                                                                                                                                                      |
|                                              | and everything you're aware that that Tuesday afternoon is that course and that that has a big | <b>Knowing when the course is on.</b> A sense that H has to manage her energy around the course.                                                                                                                      |
| Big impact of course on activity around it   | impact on what you what                                                                        | <b>Big impact of course.</b> Sounds like the course has a big impact on how she spends her time when not at the course. Any particular time?                                                                          |
|                                              | you're doing on the you know what you do on the                                                |                                                                                                                                                                                                                       |
| Mental preparation for course                | Monday sort of psych-                                                                          | <b>Day before course.</b> Big impact the day before the course. Exactly impact on what? Activity?                                                                                                                     |
|                                              | psyching yourself up to it                                                                     | <b>Psyching self up.</b> Speaks to a cognitive element here. A mental preparation.                                                                                                                                    |
| Physical (energy) preparation for course     | and making sure you-                                                                           | <b>Ensuring self is well rested.</b> Speaks to resting in preparation for attending the course.                                                                                                                       |
|                                              | you're well rested and everything and then just                                                | Disjointed speech – communicating something?                                                                                                                                                                          |
| Reducing activity around course              | nothing on the Tuesday                                                                         | <b>No activity before the session on the day of the course.</b> Seems to be talking of engaging in very little activity.                                                                                              |
|                                              | before you go having                                                                           |                                                                                                                                                                                                                       |
|                                              | nothing on in the evening                                                                      | <b>Ensuring no activity in evening post-course.</b> Again seems to be a way of minimising the activity output.                                                                                                        |
|                                              | and hopefully not having anything on the                                                       |                                                                                                                                                                                                                       |
| Course as big commitment                     | Wednesday so it is it is a                                                                     | <b>Ideal not to have activity planned day after.</b> Again, about managing time to ensure as little energy as possible is expended around the course. Repetition of 'it is' – highlighting how big the commitment is? |
|                                              | big commitment that you                                                                        | <b>Big commitment.</b> Not just a big commitment for the afternoon, but for the days preceding and following the session also.                                                                                        |
|                                              | have to be really careful I                                                                    | <b>Taking care.</b> A sense of needing to prepare so that you don't do anything damaging to yourself.                                                                                                                 |

## ***Appendix C: Recruitment flyer***

# Mindfulness and ME: What's your story?



*A project by...*

*...Jennifer Ellen Dayes...*

*... BSc, PGCert, MBPsS, and DCounsPsych student*

I am studying for a doctorate in Counselling Psychology at City University London and am conducting a research project into mindfulness and ME. I am curious to know what it is like to experience a mindfulness-based intervention if you are a person living with ME. If you are thinking "I might be interested", I would be grateful if you could consider whether you answer "yes" to the statements in the box below.

- **I am living with ME**
- **I have attended classes, a course, or therapy that employs formal mindfulness practice. This may include but is not limited to:**
  - **Mindfulness classes**
  - **Mindfulness-based stress reduction**
  - **Mindfulness-based cognitive therapy**
  - **Acceptance and commitment therapy**
  - **Compassion-focussed therapy**
- **I attended the above for six weeks or more**
- **I attended the above whilst I was living with ME**

If you answered 'yes' to all of the above, I would really like to hear from you. The project will be fully approved by my university's ethical board. If you would like share your experiences, or even just ask a little more about the project, please contact me on [REDACTED] / [REDACTED], or my research supervisor Dr Courtney Raspin at [REDACTED].

Thank you ☺

***Appendix D: Demographic questionnaire***

# Demographic Questionnaire

The purpose of this questionnaire is to gather information about you. With this information I will be able to describe the people I interviewed. For example, I will be able to say... "I interviewed 3 males and 5 females who ranged in age from 26 to 65". Information will not be used in a way which could compromise your anonymity. For example, I would **not** say "X, a 47 year old male, was recruited through Stockport ME Group and has been formally diagnosed with ME for 3 years".

Please could you answer the following...

|    |                                                                                                                                               |
|----|-----------------------------------------------------------------------------------------------------------------------------------------------|
| 1. | Age:                                                                                                                                          |
| 2. | Sex:                                                                                                                                          |
| 3. | Ethnicity:                                                                                                                                    |
| 4. | How did you learn about the study?                                                                                                            |
| 5. | How long have you experienced symptoms of ME/CFS?<br>____ years    ____ months                                                                |
| 6. | Have you ever been given a formal diagnosis of ME/CFS?<br><input type="checkbox"/> yes <input type="checkbox"/> no                            |
| 7. | If yes, how long have you had this diagnosis?<br>____ years    ____ months                                                                    |
| 8. | How would you describe your ME at present?<br><input type="checkbox"/> mild <input type="checkbox"/> moderate <input type="checkbox"/> severe |
| 9. | How would you describe your ME in general?<br><input type="checkbox"/> mild <input type="checkbox"/> moderate <input type="checkbox"/> severe |

|     |                                                                                                                                                                                                                                                                                                              |
|-----|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 10. | <p>What mindfulness-based interventions have you experienced?</p> <p><b>Intervention I:</b><br/>         From ____/____ (month/year) to ____/____ (month/year)</p> <p>Please briefly describe (e.g. 12 week course/counselling sessions/one off meditation day)</p> <p>How many sessions did you attend?</p> |
|     | <p><b>Intervention II:</b><br/>         From ____/____ (month/year) to ____/____ (month/year)</p> <p>Please briefly describe (e.g. 12 week course/counselling sessions/one off meditation day)</p> <p>How many sessions did you attend?</p>                                                                  |
|     | <p><b>Intervention III:</b><br/>         From ____/____ (month/year) to ____/____ (month/year)</p> <p>Please briefly describe (e.g. 12 week course/counselling sessions/one off meditation day)</p> <p>How many sessions did you attend?</p>                                                                 |
|     | <p><b>Intervention IV:</b><br/>         From ____/____ (month/year) to ____/____ (month/year)</p> <p>Please briefly describe (e.g. 12 week course/counselling sessions/one off meditation day)</p> <p>How many sessions did you attend?</p>                                                                  |
|     | <p><b>Intervention V:</b><br/>         From ____/____ (month/year) to ____/____ (month/year)</p> <p>Please briefly describe (e.g. 12 week course/counselling sessions/one off meditation day)</p> <p>How many sessions did you attend?</p>                                                                   |

Thank you

## ***Appendix E: Information sheet***

# Mindfulness and ME: What's your story?



## Information about the study

Thank you for expressing interest in being a participant for my research.

### **Aim:**

I hope to interview people with ME about their experiences of mindfulness-based interventions.

In order to make sure I produce valid, reliable and ethical research I have to ensure that the people I interview meet certain criteria. The first step therefore is for us to have a chat on the phone. This will last no more than ten minutes. I will ask you some questions about how you are feeling within yourself at the moment, and about current and past medical conditions.

Once we have established that you are eligible to take part we can set a date, time, and place to conduct the interview. This is likely to be sometime between February to June 2013. The interview will last an hour and will take place either in a public venue where I can ensure your comfort and confidentiality, or over the phone. At this point, I anticipate using a room at [REDACTED] or [REDACTED]. I will tape the interview. The only people with access to the recording will be myself and my thesis supervisor. I intend to transcribe the information on the recording and delete the recording straight afterwards. Transcripts will be kept in a locked cabinet and shredded on completion of my course. You can be assured that anything you disclose will remain confidential, unless I learn that you or somebody else is at risk of harm, or I learn of a crime.

The type of study I am doing means that I will quote from the interviews in my write-up. In order to ensure confidentiality, I will change your name and any information by which somebody might be able to identify you.

I intend to conduct two initial pilot interviews so that I can refine the interview process and questions for subsequent interviews. Pilot participants are asked to give feedback about their experience of the process. This will take no longer than half an hour. The feedback will be recorded and deleted on completion of my course. I will ask you whether or not you would like to take part in one of the pilot interviews when we talk over the phone.

**Possible risks:**

It is of utmost importance that you feel safe before, during, and after the study. As you will know, ME symptoms can be brought on by activity. You are very welcome to take as many breaks as you need during the study. We can spread the interview over more than one day, or can conduct the interview over the phone if needed.

It is possible that talking about your experiences could bring up emotions you are not expecting. You might like to talk to someone about these. To this end, I will give you the details of organisations that can provide you with support.

**Further information:**

Participation is completely voluntary. You can choose to withdraw from the study at any time until 24 hours after our interview.

I hope to publish my findings so that others living with and working with ME may benefit from them.

If you would like to be interviewed, or would like to find out more, please call or email me. My research supervisor is also happy to talk to you so feel free to email her as well.

Warm wishes,

Jennie                      T: [REDACTED]                      E: [REDACTED].

Research supervisor – Dr Courtney Grant-Raspin: [REDACTED]

***Appendix F: Proof of ethical approval to interview participants in their own  
homes***

## Ethics Release Form for Student Research Projects

All students planning to undertake any research activity in the School of Arts and Social Sciences are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal clearly stating aims and methodology**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

- An understanding of ethical considerations is central to planning and conducting research.
- Approval to carry out research by the Department or the Schools does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
- The published ethical guidelines of the British Psychological Society (2009) Guidelines for minimum standards of ethical approval in psychological research (BPS: Leicester) should be referred to when planning your research.
- **Students are not permitted to begin their research work until approval has been received and this form has been signed by Research Supervisor and the Department's Ethics Representative.**

### Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

Professional Doctorate in Counselling Psychology ☐

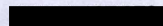
Please answer all of the following questions, circling yes or no where appropriate:

1. Title of project

How are mindfulness-based interventions experienced by people with ME/CFS?

2. Name of student researcher (please include contact address and telephone number)

Jennifer Ellen Dayes



3. Name of research supervisor

Dr Courtney Grant Raspin

4. Is a research proposal appended to this ethics release form?

No

5. Does the research involve the use of human subjects/participants?

Yes

If yes,

a. Approximately how many are planned to be involved?

Eight

b. How will you recruit them?

I have contacted [REDACTED] and the [REDACTED]. I sent an email with my flyer attached (see appendices one for my flyer). I now have enough participants.

c. What are your recruitment criteria?

*(Please append your recruitment material/advertisement/flyer)*

Participants need to be individuals living with ME/CFS, who have engaged with a mindfulness-based intervention for a minimum of six weeks during the time they have been living with ME/CFS. I intend to categorise individuals as 'living with ME/CFS' if they meet the criteria set by Fukuda et al. (1994). I intend to define 'mindfulness-based intervention' as an experience involving formal mindfulness practice and another person whose role is to introduce mindfulness theory and practice. Participants must not be experiencing suicidal thoughts or intention to self-harm. The information required to categorise individuals as 'living with ME/CFS', as having experienced a mindfulness-based intervention for a minimum of six weeks, and as not experiencing suicidal thoughts/intention to self-harm has been gathered during a telephone interview. This interview was conducted at a time that was before and separate to the research interview. To see the questions I asked during the telephone interview please refer to appendices two, the screening questions.

d. Will the research involve the participation of minors (under 18 years of age) or vulnerable adults or those unable to give informed consent?

Yes, my research involves vulnerable adults who **have** mental capacity to give informed consent. I am classing these individuals as vulnerable because the nature of their condition means that symptoms can be brought on by too much activity. Some individuals may also have physical difficulties.

d1. If yes, will signed parental/carers consent be obtained?

No

d2. If yes, has a CRB check been obtained?

*(Please append a copy of your CRB check)*

Yes. See appendices three.

6. What will be required of each subject/participant (e.g. time commitment, task/activity)? (If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).

Each participant has been required to read information about the study (see appendices four), and sometime after this, completed a ten minute telephone interview. A period of time from now, participants will be asked to fill in a consent form (see appendices five) and to post this back to me. Sometime after this, participants will take part in a research interview which will last for an hour. This will be completed face to face. Individuals can be interviewed at home, over the telephone, or in a public place. If they choose a public place they will have to travel to a venue. If individuals have volunteered to be, and selected to be, pilot participants, they will be required to give feedback about the research interview immediately after this interview has taken place. This will last half an hour maximum. Participants can choose not to be pilot participants. Participants can take breaks at any point during the process. After the interviews are complete, participants will be invited to read a debriefing form (see appendices six).

---

7. Is there any risk of physical or psychological harm to the subjects/participants?

Yes

If yes,

a. Please detail the possible harm?

Participants may talk about subjects they find upsetting.

ME/CFS symptoms are elicited/exacerbated by activity. It is possible that the activity required from participants may exacerbate their symptoms.

b. How can this be justified?

There is a strong rationale detailed in my proposal for exploring the area I am. This proposal has already been granted ethical clearance. I am submitting the current proposal to allow me to interview participants in their own homes, a facet not explored in my previous proposal.

The nature of ME/CFS is that the same level of activity will affect the symptoms of some people and not others depending on the severity of their condition. The level of activity required in my study is unlikely to be damaging to many. Participants have full mental capacity and will be aware of the effect the study could have on their symptoms. If symptoms were made worse this would be a temporary effect.

c. What precautions are you taking to address the risks posed?

Individuals will be made well aware that participation is voluntary and that they can withdraw at any time up until 24 hours after our interview.

Participants will be informed from the outset exactly how much effort the study will entail. They will be encouraged to take as many breaks as they need during the study, can spread the interview/s over more than one day, have the option of being interviewed over the phone, and can be interviewed in their own home if they prefer. Individuals can opt out of being pilot participants if they wish. Activity will be spread over time to ensure participants are not required to do too much activity on the one occasion. I.e. reading the information about the study,

engaging in the screening interview, reading and filling in the consent form, and engaging in the research/pilot interviews has been planned to occur on different days with adequate time between these days. I have provided my contact details and will urge participants to contact me if they have any questions or would like further information. A wide range of support information will be given to participants after the study has finished (see appendices six).

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

*(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)*

Yes, see appendices four.

9. Will any person's treatment/care be in any way be compromised if they choose not to participate in the research?

No

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

*(If yes please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)*

Yes, see appendices five.

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

The details I will be keeping are: one consent form, personal details including names, telephone numbers, addresses and email addresses, my written responses to the screening interview, audio-recording of the research interview and pilot interview where applicable, and transcripts of the interviews. There will also be the write up and notes connected to this.

12. What provision will there be for the safe-keeping of these records?

All information, excepting the write up and notes connected to the write up, will be kept in a locked cabinet at my house. The key will be kept in a secure location. The write up and write up notes will only contain anonymised data, hence will have no identifying information. When I am travelling with completed recordings or transcripts, for example, when on the way back from the interview venue, I will transport these in a self-addressed envelope in a zip-up bag. Consent forms will be sent back first class in a secure envelope. Research interview recordings and pilot recordings will be transcribed as soon as possible, after which they will be deleted. All other data will be destroyed after I pass my thesis and finish my course.

It will be necessary for me to share my participant's addresses with a trustworthy person if I am interviewing them in their own home. I will write the address down and give this to the trustworthy person before I leave for the interview. I will then collect this on my return and burn it.

13. What will happen to the records at the end of the project?

---

All personal and identifying data will be shredded at the end of the project. The write up will obviously not be shredded. I hope to publish my findings although this is not definite. It is likely this will require a re-writing of the project. The notes for the write up will also not be shredded, however these will contain no confidential or identifying data.

14. How will you protect the anonymity of the subjects/participants?

Due to the nature of interviews, participants cannot remain anonymous to myself. I will not share the identities of participants with anyone other than my supervisor. Participant's addresses will be shared only between myself, my supervisor, and my trustworthy person as appropriate. All identifying features in the interview data will be changed in the write up and write-up notes to ensure participant's identities remain confidential.

15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

*(Please append any de-brief information sheets or resource lists detailing possible support options)*

Participants will be provided with details of support organisations which they can contact if they feel they need further support (see appendices six). These details include websites, telephone numbers, and email addresses. There are organisations which provide support/information especially for people with ME/CFS, and organisations especially for those feeling low in mood. There is also information by which an individual could find a personal therapist.

My contact details and my supervisors contact details are also given with this information in case participants wish to contact either of us further.

If you have circled an item in **underlined bold** print or wish to provide additional details of the research please provide further explanation here:

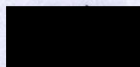
I am using human participants. I am classing people with ME/CFS as vulnerable for two reasons. Firstly, because they may have mental or physical difficulties as a result of their condition, and secondly because the nature of their condition means that symptoms can be brought on by physical activity. The mental difficulties symptomatic of ME/CFS are often called 'brain fog'. Brain fog can consist of difficulties with memory, finding words, making decisions, and 'thinking straight'. The physical difficulties symptomatic of ME/CFS can consist of irritable bowel syndrome, tender glands, mobility problems, and pain, amongst others.

A defining characteristic of ME/CFS is fatigue brought on by activity. Other symptoms such as pain and 'brain fog' can be brought on by activity also. How much activity leads to a worsening of symptoms is different for each person. It is unlikely individuals will volunteer to take part if they believe the research will be harmful to them. I therefore feel it is unlikely that the research will be harmful to those who volunteer to take part.

All participants will have full mental capacity to make an informed decision to participate. Signed parental or carer consent is therefore not necessary.

The psychological harm that participants may be at risk of pertains to distress in terms of discussing their experiences. Participants will be made well aware of the topics the interviews will focus around.

Signature of student researcher



Date

18.08.2014

**CHECKLIST:** the following forms should be appended unless justified otherwise

|                      |                          |
|----------------------|--------------------------|
| Research Proposal    | <input type="checkbox"/> |
| Recruitment Material | <input type="checkbox"/> |
| Information Sheet    | <input type="checkbox"/> |
| Consent Form         | <input type="checkbox"/> |
| De-brief Information | <input type="checkbox"/> |

### **Section B: Risks to the Researcher**

1. Is there any risk of physical or psychological harm to yourself?

Yes

If yes,

a. Please detail possible harm?

I will be meeting people I do not know to interview them, and may be meeting participants in their own homes. I am also asking people to post their consent forms back and thus will need to provide an address for them to do so.

b. How can this be justified?

I would prefer to meet people face to face as a good rapport may be easier to establish and richer data gathered than, for example, interviewing over the phone. I have given participants the option for interviewing over the phone if they prefer. However, some participants may find that talking on the phone uses more energy than talking face-to-face. People with ME/CFS only have a certain amount of energy to expend during the day before the activity they are engaging in triggers their symptoms. Meeting participants in their own homes would greatly reduce the amount of effort each participant is likely to expend, reducing the risk that the research would elicit symptoms, and leaving participants with more energy for other activities.

Asking participant's to post their consent forms back to me is part of ensuring they do not have too much to do on the one day. I considered asking participants to bring the signed form with them on the day of the interview but could not guarantee interviewees would remember. I did not want them to have to read and sign another as this would expend energy.

c. What precautions are to be taken to address the risks posed?

I have spoken to all but one of my participants over the phone and do not feel uncomfortable visiting the homes of the individuals I have spoken to. If I were to feel this, I would not go. If I feel uncomfortable whilst I am there, I will explain to my participant that I feel uncomfortable, explain why, and leave. I will inform a trustworthy person of where I am going. I will provide them with the address of the interviewee's home, and instructions outlining their role and the actions they must take (see appendices seven). I will keep a fully charged mobile phone with me at all times and will not turn this off during the interviews, instead keeping it on 'silent'. I will call in 'safe' to my trustworthy person before entering the interviewee's home, and again at an expected time when I have left the interviewee's home and have entered my car. If I do not ring in safe at the allotted time, my trustworthy person will be instructed to leave five minutes then call me. If I do not answer or return the call they will be instructed to call me again in half an

hour. If I do not answer for a second time they will be instructed to call the police, explain the situation, and give the police the participant's address.

I have decided to ask participants to post their consent forms back to me at a safe address. I have asked the manager of the service where I am on placement if participants can send their completed forms to the service address. I am waiting to hear back from the manager about this.

**Section C: To be completed by the research supervisor**

*(Please pay particular attention to any suggested research activity involving minors or vulnerable adults. Approval requires a currently valid CRB check to be appended to this form. If in any doubt, please refer to the Research Committee.)*

Please mark the appropriate box below:

Ethical approval granted ☒

Refer to the Department's Research and Ethics Committee ☐

Refer to the School's Research and Ethics Committee ☐

Signature ----- Date 18 August 2014

**Section D: To be completed by the 2<sup>nd</sup> Departmental staff member** *(Please read this ethics release form fully and pay particular attention to any answers on the form where underlined **bold** items have been circled and any relevant appendices.)*

I agree with the decision of the research supervisor as indicated above ☐

Signature ----- Date -----

## ***Appendix G: Consent form***

# Consent form

The purpose of this form is to ensure you have been given all the information you need, and to prove you have given consent to take part in the study. Please can you read each statement, tick it if you agree, and sign at the bottom.

- ☐ I understand that the aim of the questionnaire is to gather information about me
- ☐ I understand that the aim of the interview is to explore my experiences of mindfulness-based intervention(s)
- ☐ I understand that the interview will last for an hour, and will last an extra half-hour if I am a pilot participant
- ☐ I understand that the interview will involve lots of talking
- ☐ I understand that I can take a break whenever I need to, and can choose to split the interview over more than one day
- ☐ I understand that my participation is voluntary
- ☐ I understand that I can withdraw from the study until 24 hours after the interview
- ☐ I understand that my information will be anonymous to all but the research team. The research team includes the researcher, her supervisor, and any other person the researcher decides necessary to have access to my information. The researcher will act according to the Data Protection Act 1998. She will not share any of your information with the research team unless she deems it absolutely necessary
- ☐ I understand that the researcher may break the above terms of anonymity should she learn that any person is at risk of harm, or should she learn information about a crime
- ☐ I understand that my information will be kept either in a safe place or password protected and will be destroyed when it is no longer needed. In accordance with the Data Protection Act 1998, the researcher may keep my information for seven years from the date it was given.
- ☐ I have received sufficient information about the questionnaire, interview, and my participation
- ☐ I have had all my questions answered satisfactorily
- ☐ I fully consent to take part in the study

---

Participant's name:

Researcher's name: Jennifer Dayes

Participant's signature:

Researcher's signature:

Date:

265

Date:

## ***Appendix H: Safety information***

## Instructions for safeguarding

### **For all interviews**

Your role in this process is to ensure I am as safe as I can be whilst conducting the interviews for my thesis. There are a number of steps I would like you to follow to assist me in this process.

Before I leave to travel to the interview I will give you the address of where I am going.

*Step 1: Keep this safe, do not copy it, and know where it is at all times*

I will ring you when I have arrived at the venue, before I enter it.

*Step 2: Keep your mobile phone on and about your person. Expect this call. If I do not phone you at the expected time, leave five minutes then call me. If I do not pick up or return your call within half an hour, call me again. If I do not pick up, call the police. 101 is the number for a non-emergency incident.*

I will call you when I have finished the interview at an allotted time.

*Step 3: Keep your mobile phone on and about your person. Expect this call. If I do not phone you at the expected time, leave five minutes then call me. If I do not pick up or return your call within half an hour, call me again. If I do not pick up, call the police. 101 is the number for a non-emergency incident.*

I will come and collect the address of the interview venue from you.

*Step 4: Ensure that you have given me this address back*

**You must not share the address I have given you with anyone  
unless you are worried for my safety**

### **For today's interview**

Time I am due to conduct the interview (from/till):

Time I will call you when I have arrived at the venue:

Time I will call you when I have left the venue:

Time I will collect the address of the venue from you:

My mobile number:

Number I will call you on:

Back up number I will call you on if I do not get through:

Participant's address:

## ***Appendix I: Preparation checklist***

## **Interview checklist**

### **Before**

- Two Dictaphones in a self-addressed envelope
- Mobile phone (fully charged)
- Address written down and given to trustworthy person
- Instructions given to trustworthy person
- Copy of instructions to take with me
- Contact numbers for trustworthy person
- Interview schedule
- Debriefing sheet
- Notepad
- Three pens
- Telephone number of participant
- Address of venue
- SatNav
- Petrol in car, tyres pumped up, windscreen washer in
- Copy of question schedule for pilot participants
- Consent Form
- Demographic Questionnaire
- Watch

### **During**

- Phone in 'safe' to trustworthy person at appointed time before entering the venue
- Phone in 'safe' to trustworthy person at appointed time after back in car

### **After**

- Complete researcher debriefing questions

## ***Appendix J: Debriefing framework***

### **Interviewer debrief**

1. Were there any instances where I found it difficult to bracket off my own pre-existing concerns, hunches, and theoretical hobby horses?
2. Did I find it difficult not to intervene in the opening phase? Were there any times where the participant needed assistance and I intervened to keep the conversation going?
3. Were there times where I abandoned the structure or switched the questions around? Why did I do this?
4. Did I make any notes of key words or topics when the participant was in full flow and go back to these afterwards?
5. Did I ask any 'obvious' questions (questions about things which at face value I thought I understood)?
6. How do I think the interview went? Why?
7. What do I feel now?
8. Are there any comments or anything else I would like to touch on not talked about above?

***Appendix K: Ethics release form***

## Ethics Release Form for Student Research Projects

All students planning to undertake any research activity in the School of Arts and Social Sciences are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal clearly stating aims and methodology**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

- An understanding of ethical considerations is central to planning and conducting research.
- Approval to carry out research by the Department or the Schools does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
- The published ethical guidelines of the British Psychological Society (2009) Guidelines for minimum standards of ethical approval in psychological research (BPS: Leicester) should be referred to when planning your research.
- **Students are not permitted to begin their research work until approval has been received and this form has been signed by Research Supervisor and the Department's Ethics Representative.**

### Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

Professional Doctorate in Counselling Psychology

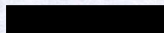
Please answer all of the following questions, circling yes or no where appropriate:

1. Title of project

How are mindfulness-based interventions experienced by people with ME/CFS?

2. Name of student researcher (please include contact address and telephone number)

Jennifer Ellen Dayes



3. Name of research supervisor

Dr Courtney Grant Raspin

4. Is a research proposal appended to this ethics release form?

Yes

5. Does the research involve the use of human subjects/participants?

Yes

If yes,

a. Approximately how many are planned to be involved?

Twelve

b. How will you recruit them?

My aim is to target local support groups for people with ME/CFS such as [REDACTED] the charities [REDACTED] and [REDACTED] and organisations who run mindfulness courses such as [REDACTED] and [REDACTED]. I have contacts at [REDACTED] and [REDACTED]. I intend to use 'snowball' sampling via my contacts. I will also advertise in [REDACTED] quarterly magazine [REDACTED] and if possible, [REDACTED] quarterly magazine [REDACTED]. The flyer I will use to do this with is attached in appendices two. If I still need more participants I will attempt to advertise on the [REDACTED] website. I will write the advertisement for the website if and when I have had confirmation I can advertise this way.

c. What are your recruitment criteria?

*(Please append your recruitment material/advertisement/flyer)*

Participants need to be individuals living with ME/CFS, who have engaged with a mindfulness-based intervention for a minimum of six weeks during the time they have been living with ME/CFS. I intend to categorise individuals as 'living with ME/CFS' if they meet the criteria set by Fukuda et al. (1994). I intend to define 'mindfulness-based intervention' as an experience involving formal mindfulness practice and another person whose role is to introduce mindfulness theory and practice. Participants must not be experiencing suicidal thoughts or intention to self-harm. The information required to categorise individuals as 'living with ME/CFS', as having experienced a mindfulness-based intervention, and as not experiencing suicidal thoughts/intention to self-harm will be gathered during a telephone interview. This interview will be conducted at a time which is before and separate to the research interview. To see the questions I will ask during the telephone interview please refer to appendices one, the screening questions.

d. Will the research involve the participation of minors (under 18 years of age) or vulnerable adults or those unable to give informed consent?

Yes, my research will involve vulnerable adults who **have** mental capacity to give informed consent. I am classing these individuals as vulnerable because the nature of

their condition means that symptoms can be brought on by too much activity. Some individuals may also have physical difficulties.

d1. If yes, will signed parental/carer consent be obtained?

No

d2. If yes, has a CRB check been obtained?  
(Please append a copy of your CRB check)

- We need to check that if you answer 'yes' you need CRB?

I have not applied for a CRB check for this research.

6. What will be required of each subject/participant (e.g. time commitment, task/activity)? (If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).

Each participant will be required to read information about the study (see appendices four), then, at a later date, complete a ten minute telephone interview. Sometime after this interview, on a different occasion, participants will take part in a research interview which will last for an hour and can be completed either face to face, or over the phone. Individuals who choose to meet face to face will have to travel to a venue in which to do so. Before the research interview starts, they will be asked to read and sign a consent form (see appendices five). If individuals have volunteered to be, and selected to be, pilot participants they will be required to give feedback about the research interview immediately after this interview has taken place. This will last half an hour maximum. Participants can choose not to be pilot participants. Participants can take breaks at any point during the process. After the interviews are complete, participants will be invited to read a debriefing form (see appendices six).

---

7. Is there any risk of physical or psychological harm to the subjects/participants?

Yes

If yes,

a. Please detail the possible harm?

Participants may talk about subjects they find upsetting.

ME/CFS symptoms are elicited/exacerbated by activity. It is possible that the activity required from participants may exacerbate their symptoms.

b. How can this be justified?

There is a strong rationale detailed in my proposal for exploring the area I am.

The nature of ME/CFS is that the same level of activity will affect the symptoms of some people and not others depending on the severity of their ME/CFS. The level of activity required in my study is unlikely to be damaging to many. Participants have full mental capacity and will be aware of the effect the study could have on their symptoms. If symptoms were made worse this would be a temporary effect.

c. What precautions are you taking to address the risks posed?

---

Individuals will be made well aware that participation is voluntary and that they can withdraw at any time up until 24 hours after our interview.

Participants will be informed from the outset exactly how much effort the study will entail. They will be encouraged to take as many breaks as they need during the study, can spread the interview/s over more than one day, and can conduct the entire process over the phone if needed. Individuals can opt out of being pilot participants if they wish. Activity will be spread over time to ensure participants are not required to do too much activity on the one occasion. I.e. reading the information about the study, engaging in the screening interview, and engaging in the research/pilot interviews will occur on different days with adequate time between these days. I have provided my contact details and will urge participants to contact me if they have any questions or would like further information. A wide range of support information will be given to participants after the study has finished.

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?  
*(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)*

Yes, see appendices four.

9. Will any person's treatment/care be in any way be compromised if they choose not to participate in the research?

No

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?  
*(If yes please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)*

Yes, see appendices five.

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

The details I will be keeping are: one consent form, personal details including names, telephone numbers, addresses and email addresses, my written responses to the screening interview, audio-recording of the research interview and pilot interview where applicable, and transcripts of the interviews. There will also be the write up and notes connected to this.

12. What provision will there be for the safe-keeping of these records?

All information, excepting the write up and notes connected to the write up, will be kept in a locked cabinet at my house. The key will be kept in a secure location. The write up and write up notes will only contain anonymised data, hence will have no identifying information. When I am travelling with completed consent forms and recordings, for example when on the way back from the interview venue, I will transport data in a self-addressed envelope in a zip-up bag. Research interview

recordings will be transcribed as soon as possible, after which they will be deleted. Pilot recordings will be deleted on completion of my course. All other data will be destroyed after I pass my thesis and finish my course.

13. What will happen to the records at the end of the project?

All personal and identifying data will be shredded at the end of the project. The write up will obviously not be shredded. I hope to publish my findings although this is not definite. It is likely this will require a re-writing of the project. The notes for the write up will also not be shredded, however these will contain no confidential or identifying data.

14. How will you protect the anonymity of the subjects/participants?

Due to the nature of interviews, participants cannot remain anonymous to myself. I will not share the identities of participants with anyone other than my supervisor. All identifying features in the interview data will be changed in the write up and write-up notes to ensure participant's identities remain confidential.

15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

*(Please append any de-brief information sheets or resource lists detailing possible support options)*

Participants will be provided with details of support organisations which they can contact if they feel they need further support (see appendices six). These details include websites, telephone numbers, and email addresses. There are organisations which provide support/information especially for people with ME/CFS, and organisations especially for those feeling low in mood. There is also information by which an individual could find a personal therapist.

My contact details and my supervisors contact details are also given with this information in case participants wish to contact either of us further.

If you have circled an item in **underlined bold** print or wish to provide additional details of the research please provide further explanation here:

I am using human participants. I am classing people with ME/CFS as vulnerable for two reasons. Firstly, because they may have mental or physical difficulties as a result of their condition, and secondly because the nature of their condition means that symptoms can be brought on by physical activity. The mental difficulties symptomatic of ME/CFS are often called 'brain fog'. Brain fog can consist of difficulties with memory, finding words, making decisions, and 'thinking straight'. The physical difficulties symptomatic of ME/CFS can consist of irritable bowel syndrome, tender glands, mobility problems, and pain, amongst others.

I do not feel it necessary to apply for a CRB specific to this research.

A defining characteristic of ME/CFS is fatigue brought on by activity. Other symptoms such as pain and 'brain fog' can be brought on by activity also. How much activity leads to a worsening of symptoms is different for each person. It is unlikely individuals will volunteer to take part if they believe the research will be harmful to them. I

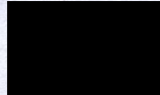
I agree!!  
let's check out proposal!!

therefore feel it is unlikely that the research will be harmful to those who volunteer to take part.

All participants will have full mental capacity to make an informed decision to participate. Signed parental or carer consent is therefore not necessary.

The psychological harm that participants may be at risk of pertains to distress in terms of discussing their experiences. Participants will be made well aware of the topics the interviews will focus around.

Signature of student researcher



Date 29.11.2012

**CHECKLIST:** the following forms should be appended unless justified otherwise

Research Proposal ✓  
Recruitment Material ✓  
Information Sheet ✓  
Consent Form ✓  
De-brief Information ✓

### Section B: Risks to the Researcher

1. Is there any risk of physical or psychological harm to yourself?

Yes

If yes,

a. Please detail possible harm?

I will be meeting people I do not know to interview them.

b. How can this be justified?

Participants may find meeting face to face less effort than talking over the phone. I would prefer to meet people face to face as a good rapport may be easier to establish. I find it easier to steer conversation face to face rather than over the phone, hence anticipate generating richer data in this way.

c. What precautions are to be taken to address the risks posed?

I have decided not to meet people in their homes. I will meet them in a public place, probably the local library or hospital. I will inform a trustworthy person of where I am going and what I will be doing. I will keep a fully charged mobile phone about my person at all times. I will ring in 'safe' at an allotted time, a call this person will be expecting. If I do not call them they will call me. If I do not answer within the hour, they will call the police.

### Section C: To be completed by the research supervisor

(Please pay particular attention to any suggested research activity involving minors or vulnerable adults. Approval requires a currently valid CRB check to be appended to this form. If in any doubt, please refer to the Research Committee.)

Please mark the appropriate box below:

Ethical approval granted ☒

Refer to the Department's Research and Ethics Committee

Refer to the School's Research and Ethics Committee

Signature

[Redacted Signature]

Date

6/12/12

**Section D: To be completed by the 2<sup>nd</sup> Departmental staff member**

(Please read this ethics release form fully and pay particular attention to any answers on the form where underlined bold items have been circled and any relevant appendices.)

I agree with the decision of the research supervisor as indicated above

Signature

Date

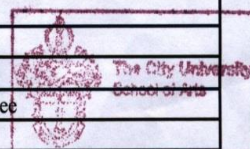
***Appendix L: Insurance form***

All students planning to undertake any research activity in the Schools of Arts and Social Sciences are required to complete this Insurance Data Collection as part of their ethical approval application.

|                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|--------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Researcher(s) Names(s)                                                   | Jennifer Ellen Dayes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| Supervisor(s) Name(s)                                                    | Dr Courtney Grant Raspin                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| Degree Programme                                                         | Professional Doctorate in Counselling Psychology                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| Project Title                                                            | How are mindfulness-based interventions experienced by people with ME/CFS?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Abstract<br>(maximum 100 words)                                          | Practitioners currently use mindfulness-based approaches with clients living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome despite a minute evidence base for its use in this population. We currently know very little about how interventions based on mindfulness are experienced by people with ME/CFS. I ask: how do people with ME/CFS experience mindfulness-based interventions. I hope to provide a rich and detailed answer to this question, informing therapeutic practice and adding to an evidence base. I have recruited individuals who have engaged in mindfulness-based intervention(s) via a support group and an organization who provide mindfulness-based training, courses, and groups. I intend to conduct semi-structured interviews and use IPA to analyze the data from these. |
| Brief descriptions of method of recruitment, procedures and participants | I have recruited eight participants. All participants are living with ME/CFS and have experienced a mindfulness-based intervention for six or more weeks. I recruited by use of a flyer which was emailed to the mailing lists held by a mindfulness organization, and handed out after a talk I gave to a local support group. I intend to interview six individuals for an hour, and two pilot individuals for an hour and a half. Pilot interviewees will be asked for feedback regarding the initial interview process as well as their experiences of mindfulness-based interventions. I have conducted a 'dress rehearsal' of the interview process with a friend to practice my interviewing technique and safety procedures.                                                                                |
| Expected end date of project                                             | January 2013                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| Will the research involved involve children or vulnerable groups?        | This research will not involve children but will involve vulnerable people. The nature of the participant's condition means that too much activity can exacerbate symptoms. Some individuals may also have physical impairments as a result of their condition.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Will the research take place abroad?                                     | No                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |

For office use only

|                                   |                                           |
|-----------------------------------|-------------------------------------------|
| Application reference             | PSYETH(UPTD) 12/13 64                     |
| Application submission date       | 28 <sup>th</sup> May 2013                 |
| Application approval date         | 7 <sup>th</sup> June 2013                 |
| Approving body                    | Department of Psychology Ethics Committee |
| External ethical approval sought? | NO                                        |
|                                   | Body (e.g. NRES):                         |



***Appendix M: Participant debriefing form***

Thank you for taking part in this study. If you wish to contact me further, my details are [REDACTED] / [REDACTED]. If you wanted to you could also contact my supervisor Courtney at [REDACTED].

Below are details of organisations you may wish to contact if you would like to talk things through further.

*Myalgic Encephalomyelitis/Chronic Fatigue Syndrome:*

**The ME Association**

**[www.meassociation.org](http://www.meassociation.org)**

The ME Association provides “information, support and practical advice for people who are affected by ME/CFS/PVFS, their families and carers”.

**ME Connect**

**0844 576 5326**

ME Connect is a helpline run by the ME Association that provides information and support. It is open every day 10am-12noon, 2-4pm, and 7-9pm.

**Email ME Connect**

**[meconnect@meassociation.org.uk](mailto:meconnect@meassociation.org.uk)**

ME Connect also has an email facility to give out information. Emails are “responded to as soon as possible between 9am and 5pm on weekdays, excluding public holidays”.

**Local Groups**

Details of local support groups can be found on the ME Association’s website. Follow the ‘information and support’ tab on the homepage then select ‘find a local support group’.

**Action for ME**

**[www.afme.org.uk](http://www.afme.org.uk)**

Action for ME provides “information and support to people affected by ME”.

**AFME Telephone Support Service**

**0845 123 2314**

Action for ME runs a helpline offering support, understanding and information. It is open 11am-3pm Monday, Thursday and Friday. Closed on bank holiday.

**AFME Email Support Service**

**[support@actionforme.org.uk](mailto:support@actionforme.org.uk)**

Action for ME also has an email facility which provides “information on ME/CFS, details of local NHS services for ME” and support for people with ME and carers. It can take up to 7 days to respond.

*Lowness in Mood:*

**SANE**

**[www.sane.org.uk](http://www.sane.org.uk)**

SANE is a mental illness charity which provides “emotional support, practical help and information”.

**SANE Helpline**

**0845 767 8000**

The SANE helpline offers “support and information to anyone affected by mental illness”. It is open every day of the year from 6pm to 11pm.

**SANEmail**

**[http://www.sane.org.uk/what\\_we\\_do/support/email/](http://www.sane.org.uk/what_we_do/support/email/)**

SANE have an email service which provides “a confidential space for you to tell us about your situation and feelings”. SANEmail aims to “provide warm, accepting and empathic responses that provide emotional support and help you explore the options available to you”. SANEmail is accessed via their website.

**Samaritans**

**[www.samaritans.org](http://www.samaritans.org)**

Samaritans provides “confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide”.

**Samaritans Helpline**

**0845 7909 090**

The Samaritans helpline offers emotional support. They are open 24 hours a day, every day of the year.

**Samaritans Email**

**[jo@samaritans.org](mailto:jo@samaritans.org)**

Emails are kept confidential and will be responded to within 12 hours every day of the year.

**General:**

**British Association for Counselling and Psychotherapy (BACP)**

To find a therapist call **01455 883 316**, or visit **[www.bacp.co.uk](http://www.bacp.co.uk)** and select ‘find a therapist’.

**British Psychological Society (BPS)**

To find a therapist visit **[www.bps.org.uk](http://www.bps.org.uk)** and select ‘find a psychologist’ under the ‘psychology and the public’ menu.

***Appendix N: Questions for pilot participants***

### **Pilot question schedule**

1. Can you tell me about your experience of the interview?

*Possible prompts: What was the interview like for you? What did you think? What did you feel?*

2. [Give interviewee's a copy of the interview question schedule]. How did you find the interview questions?

*Possible prompts: Do any questions stand out for a particular reason? What did you think about the questions?*

3. Is there any other information you would like to give me about the interview process?

*Possible prompts: Does anything else come to mind that you would like to tell me?*

***Appendix O: Extracts from reflective diary***

"I am now making up my initial question schedule. Although I am positive I want to ask people about experience, I have not been sure exactly what parts of experience I want to know about. I know that there are some which are definite – I want to gather demographic information about my participants, their ME, and their MBI experience. I also want to know about how the person experienced the other whose role it was to introduce and guide the MBI. I want to know if the MBI affected life with ME, and if so, how. I want to know if the MBI continues to influence life with ME, and if so, how."

and

"I am making notes on Nadia's transcript (I'm around line 682) and I'm noticing some new information coming out which gives me a sense of intimacy between the client and the facilitator. I am finding this sense through Nadia referring to the facilitator by her first name, and telling me about how she (the facilitator) incorporated literature she found personally inspirational into the sessions. This speaks to me like a different facet/subtheme of the therapeutic relationship."

and

"I'm on line 1132 of Lucy's analysis, and I have coded 'self as different to group members' as an emergent theme. I have also just coded 'group as sharing common struggles' as an emergent theme on line 1119, and am struck by the contrast between them. It seems there is simultaneously a sense of sameness and difference which Lucy describes. She understands that some of her experiences (such as her illness symptoms) are different, yet, many of her experiences (such as struggling with these) are the same."

***Appendix P: Question schedule***

1. Can you tell me why you volunteered to be interviewed?

*Possible prompts: What does the interview mean to you? Why did you reply to my flyer/email?*

2. Can you tell me, in your own words, what you understand a mindfulness-based intervention to be?

*Possible prompts: What is the aim? What happens? Why would somebody attend one? If you were writing an article explaining what mindfulness-based interventions are all about, what kind of things would you say?*

3. Can you tell me what it was like to attend the mindfulness-based intervention?

*Possible prompts: How did you experience the mindfulness-based intervention? How did you feel? What did you think?*

4. There may not be, but were there elements you found particularly positive, or particularly less positive about the mindfulness-based intervention? Can you tell me about this?

*Possible prompts: Did you experience any elements as especially helpful, especially desirable, especially less useful, or especially difficult? Perhaps the experience was fairly middling?*

5. Did the mindfulness-based intervention influence what it is like to live with ME/CFS or did it have no influence? Can you tell me about this?

*Possible prompts: Did the mindfulness-based intervention have an effect on life with ME/CFS or did it have no effect? How do you think life would be if you had not gone to the mindfulness-based intervention?*

6. Is there anything you would like to elaborate on, or anything you would like to share that we have not talked about?

*Possible prompts: Is there anything you would like to say more about, or anything that we have not covered that you would like to?*

7. We're coming towards the end of the interview now. How have you found it?

General prompt: Can you tell me a bit more about that?

General probe: What do you mean by X?