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Mindfulness for the Self-Management of Negative Coping, Rumination and Fears of Compassion in People with Cancer: A Mixed Methods Feasibility Study

CITY UNIVERSITY
LONDON

Sian Williams

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

City, University of London Department of Psychology, August 2021

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Cultivating self-compassion in a survivor of sexual abuse: a pluralist approach (REDACTED FOR CONFIDENTIALITY REASONS)

CITY
UNIVERSITY OF LONDON
EST 1894

City, University of London
Northampton Square
London
EC1V 0HB
United Kingdom

T +44 (0)20 7040 5060

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Declaration

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Abstract

Background

The psychological impact of living with and beyond cancer can be considerable. Evaluations of mindfulness-based interventions (MBIs) suggest beneficial effects in anxiety, depression and distress in those with the disease. However, there is little research into whether a cancer-specific MBI helps with the self-management of negative coping, rumination and fears of compassion.

Aims

Exploring the perceived impact of a tailored, mindfulness-based intervention on coping, ruminating and fears of compassion in those with cancer, by examining inter and intra-individual change in a mixed-methods, sequential explanatory design.

Methods

A single group, non-experimental, repeated measures study of 22 participants across six cancer care centres investigated the efficacy of an eight-week Mindfulness-Based Cognitive Therapy for Cancer (MBCT-Ca) course. The Reliable Change Index (RCI) examined significant improvement, deterioration, or no change in individuals on the Mental Adjustment to Cancer Scale (MACS), the Ruminative Responses Scale (RRS) and the Fears of Compassion Scale (FCS). Qualitative interviews with ten participants were analysed using Reflexive Thematic Analysis.

Results

Results suggest a significant decrease in negative adjustment to cancer, depressive, and brooding rumination (ranges: p <0.001 to p <0.05, t = - 2.65 to 6.71, d = 0.3 – 0.5) and fears of compassion towards the self (p <.05, z = -2.019, d = 0.4) post-MBI. There was a strong relationship between fearing self-compassion, accepting it or showing it to others (p <.001), and ruminative thinking (p <.001). Most participants (n = 18) reported significant positive change in at least one measure, however many acknowledged that both compassion and mindfulness can be challenging in the face of cancer.

Discussion

Findings indicate that the MBCT-Ca programme can significantly reduce negative coping, ruminating and fears of self-compassion, potentially improving psychological health and wellbeing in cancer survivors.

Implications

The psycho-social benefits of a disease-specific MBI can be wide-ranging. However, established protocols, experienced teachers and an understanding of the complexity of emotions in the context of cancer, are crucial to its efficacy.

Section A:

Introduction to the Portfolio

“Compassion gives us the courage and wisdom to descend into our suffering”
Professor Paul Gilbert

‘Compassion’ is the theme that unites this portfolio. The APA defines it as “a strong feeling of sympathy with another person’s feelings of sorrow or distress, usually involving a desire to help or comfort that person.” (APA, n.d.) It should feel natural: we are, after all, a profoundly care-giving species, evolution dictating that we look after our young, and our community, to further our survival. Darwin believed sympathy was our strongest instinct and that those who show kindness and benevolence to others who are struggling, flourish best (Darwin, 1871). Easy, supposedly, to give compassion to others but why does it sometimes feel so hard to accept it *from* them, or to show it to ourselves? Perhaps because ‘sympathy’ may invoke pity, suggestive of a power imbalance which puts us in a place of dangerous vulnerability. Perhaps we have never felt the safety of non-judgemental kindness, so our physiology and neural networks remain underdeveloped. Perhaps, rather than being suggestive of warmth and care, compassion triggers distrust, threat, and fear. It can open the door to pain, rekindling old hurts. Far better, it may seem, to keep that door shut.

Self-compassion may have a whiff of indulgence to it, an air of self-pity, an unpleasant trait in a culture that values a stiff upper lip, of keeping calm and carrying on. While I grew up in a household that was caring, more emphasis was placed on the stoic virtues of wisdom, justice, courage, and moderation. All life is shaded with suffering and mine was no different. After my third son was born blue and flat, after my Mum died suddenly of cancer, after my marriage failed, after my heart stopped on an operating table, after cancer, my default in recovery was to be brave, strong, and moderate in emotion. I was practised at that and good, I thought, at showing compassion to others, but accepting it meant weakness or failure and embracing self-kindness was unthinkable. After all, my self-critical voice was a driving force; it was useful, defining, kept me from lapsing into laziness or irresponsibility.

That harsh self-judgment, that refusal to reach for an outstretched hand, was something I also saw in others in my profession as a journalist, where a bright and brittle confidence and a refusal to reflect on the difficult story, eventually left some of my colleagues broken and unable to work. I trained as a trauma assessor, spent two years doing an MSc in Psychology and began this Doctorate to better understand the processes involved in recovery after difficult events. My experience of breast cancer led me to help those living with and beyond the disease, both in a charity care centre and in the NHS, where I witnessed how easy some found it to judge themselves, yet how emotionally distressing it felt, to accept compassion. We often worked with Paul Gilbert's Compassion-Focused Therapy (2009), which encourages individuals to balance their threat and drive systems with soothing, something many found hard to embrace. The threat and drive systems were keeping them alive, they believed, the soothe would have to wait.

Cancer is a well-researched topic; patients are often tested to see which psychological therapies may work, and compassion has also been extensively studied, but I was curious about how the disease and the concept of kindness, fit together. What does compassion mean to the individual behind the hospital number? How does it show itself? What might the resistances be? What do those with cancer say about their experiences and what help might be helpful? The gaps are where my Doctoral research began, yet it was a conversation, a decade earlier, that led me to mindfulness as a way of approaching the compassionate self in cancer.

Ten years ago, Andy Puddicombe was a former Buddhist monk, trying to get people interested in meditation by launching 'Headspace'. He encouraged me to try mindfulness. I bought a CD (not his), was profoundly irritated by the soft and soothing tones of the teacher, and decided it was not for me. I downloaded his app when I was diagnosed and it got me through some tricky times in hospital, but used as a distraction, rather than an immersion, a withdrawal from, rather than a facing toward. A few years later and this ancient practice seemed be everywhere in bite-sized, digestible pieces. ‘Mindfulness-on-the-go’ had become part of corporate culture, encapsulated in memes and social media, often presented as a panacea to those with a busy, acquisitive lifestyle, along with a smoothie and a spin class. What then, could it possibly offer those who were facing a disease which threatened their existence? Yet, there was an eight-week mindfulness course for those with cancer, running in the support centre where I was working as a trainee counselling psychologist, which seemed to be making a difference to individuals with the disease who were struggling with psychological distress. I was intrigued to understand how it might shift thoughts, feelings, and sensations for those with a ruminative, negative, and perhaps, non-compassionate mind frame. This, then, became Section B of the Portfolio, initially driven by a healthy scepticism and a journalist’s nose to understand the who, what, when, where and why of mindfulness, compassion, and cancer.

Section C is not about cancer, but it is about the struggle to accept compassion and how mindfulness helped when voicing trauma felt too threatening. Sofia, a young student with a highly self-critical voice, came to me for help with anxiety, stress, and procrastination. During our work together, shame and disgust began to show itself, then fractured memories of years of adolescent sexual abuse. Kindness had not been modelled to Sofia, her childhood was one of rejection, inconsistency and anger, her strong and deeply enmeshed safety strategies were dissociation, avoidance, and withdrawal. She feared to trust and was scared to talk. Even our mindful moments, our pauses, and attending to the ‘here and now’ and the bodily felt senses were too much at first. Sofia’s progression towards acceptance and self-compassion came haltingly and beautifully; expressed in art and demonstrated in courage. I was honoured to be invited into Sofia's life and humbled that she gave me permission to share her experiences, just as I am grateful to all those who spoke so honestly about why cancer made it so difficult to accept kindness, and how the curiosity, intention, attention, and the presence of mindfulness helped them get there. **THIS SECTION HAS BEEN REDACTED FROM THE PORTFOLIO FOR CONFIDENTIALITY REASONS**

Finally, Section D is the paper submitted to the *European Journal of Cancer Care* which sums up the main quantitative findings of my study and adds to, and extends the research into rumination, coping and compassion in cancer after a mindfulness-based intervention. I would like this research to be beneficial to Counselling Psychology as a discipline, to those working within it and to individuals struggling with psychological distress, for whom acceptance and self-compassion may help. As I was putting this portfolio together, I enrolled on an eight-week mindfulness course myself, to better understand the path my participants had taken, with all their struggles, complexities, and nuances. My experience is not theirs but just as they are gently turning towards, just as they begin to observe their struggles with kindness, just as they start to tentatively accept their "one wild and precious life", so perhaps, do I.

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Section B:

Research component

Mindfulness for the Self-Management of Negative Coping, Rumination and Fears of Compassion in People with Cancer: A Mixed Methods Feasibility Study

Chapter One: Introduction

1.1 Introduction: general overview

Every day in the UK, around one thousand people receive a diagnosis of cancer (ONS, 2018). Although still the most common cause of death, survival rates are the highest they have ever been, and of the three million people currently living with cancer, half (50%) will survive their disease for ten years or more (Cancer Research UK, 2021; Macmillan Cancer Support, 2019a). Cancer and its treatments do not just impact physical health, they have the potential to significantly impact mental health too, provoking feelings of anxiety, depression, and distress, which can last long after treatment is over (Carlson et al., 2004; Mitchell et al., 2011). Individuals can experience the fear of recurrence more than five years post-treatment (Lengacher et al., 2012) and more than half will have a psychological issue a decade after treatment ends (Macmillan Cancer Support, 2009).

The NHS England Long Term Plan pledges to diagnose earlier, keep people living longer, and support their psychological and emotional wellbeing (NHS England, 2020). However, although the National Institute for Health and Care Excellence (NICE) recommends psychological interventions within the NHS for those living with cancer (NICE, 2004, 2016), around half of those experiencing it (49%) have never been offered psychological support or advice (Mental Health Foundation [MHF], 2018). Depression and anxiety remain significantly higher for those living with disease than the general population, but few have access to mental health professionals and some 'Improving Access to Psychological Therapies' (IAPT) services do not have staff sufficiently trained to recognize and deal with cancer's complexities (Pitman et al., 2018).

Unresolved mental health issues in people with cancer lead to more frequent GP and hospital visits, with associated increases in social and health care costs (Bultz & Carlson, 2006). With more people being diagnosed and greater numbers surviving for longer, there is a huge emotional, financial, and societal cost to neglecting the psychological needs of those with the disease and a clear gap that Counselling Psychology can help to fill. The profession's stated aim is to reduce psychological distress while promoting individuals' wellbeing, with a focus on their subjective experience, using a broad definition of research which encompasses both qualitative and quantitative approaches (BPS, 2018). Much of the current literature on distress in those with cancer are quantitative studies and while interventions to help those with the disease can be rigorously and comprehensively examined in such studies, it is important not to lose the voice of those at the heart of care. Researchers in the psychosocial cancer care field, suggest that mixed methods can offer a holistic approach and capture the richness, context and meaning for those experiencing the disease (Wyatt & Hulbert-Williams, 2005) and the approach is increasingly popular in health sciences (Creswell & Plano Clark, 2017; Klassen et al., 2012) as it prioritises the construction of the individual's experience (Radley, 1999).

One of the most rapidly emerging influences in the healthcare field are mindfulness-based interventions (MBIs). Although mindfulness is a practice with its roots in Buddhism stretching back two and a half thousand years, it has only been within the last 40 that it has been standardized for Western healthcare. Mindful individuals are said to be less depressed, with research in a student cohort suggesting it can help lower brooding or depressive ruminative thinking, and improve levels of self-compassion (Svendsen et al., 2016). The idea of self-compassion as a buffer against adversity is relatively new in psychopathology, but research in those with breast cancer suggests that self-kindness activates the resting system and suppresses the threat system, allowing for lower rumination and anxiety (Brown et al., 2019). The threat response is described in Gilbert's (2009) theory of compassion as one of three main neurobiological systems: threat, drive/acquisition, and soothe/rest. The *threat* system is said to stimulate a sympathetic and adrenal response, triggering a fight or flight reaction; *drive* or acquisition, sometimes triggered by threat, is linked to goal pursuit and the *soothe*, or resting system activates the parasympathetic system, facilitating the release of endorphins and oxytocin, suppressing the threat response (Gilbert, 2017). Thus, the theory suggests self-compassion can deactivate the threat system by stimulating self-soothing (Gilbert & Irons, 2005). While studies suggest self-compassion is related to better psychological functioning in those with cancer, acting as a buffer against threats of depression and rumination (Pinto-Gouveia et al., 2013), less is known about how mindfulness might influence this, or the mechanisms, processes and relationships involved.

In this chapter, a broad review of recent literature will be set out, touching on the social, cultural, contextual, and biological aspects of cancer and the studies suggesting how mindfulness interventions can help those struggling psychologically. It will look at how the current literature has contributed to research into mindfulness, examine the concepts and constructs of rumination and compassion, and suggest ways that this study may add to that knowledge. The research itself takes a pragmatic, pluralistic, and critical realist stance, underpinned by an existential ontology which regards suffering, uncertainty, disease, and death as an essential part of our 'being-in-the-world' (Heidegger, 1962, p. 78). However, although pain is acknowledged to be part of life, one of the key epistemological assumptions made in this study is that our experiences of cancer and emotional reactions to it are socially constructed and mediated through language, culture, and social interaction (Willig, 1999, 2012). This amounts to a social constructivist approach (Crotty, 1998) consistent with a critical realist position (Willig, 1999, 2016), which balances the role of the particular social and material context within which meaning making takes place, with the fact that everyone perceives the world differently (Braun & Clarke, 2006).

The research has two stages; the first is a quantitative study, examining coping, rumination, and fears of compassion in those with cancer before and after a mindfulness-based intervention in a cancer support setting. The second stage is a phenomenological and thematic inquiry into the experiences of participants who reported a shift in these concepts after the eight-week course. It takes a constructivist perspective when investigating the process and mechanisms of any change, assuming an individual's meaning making is both actively and socially constructed (Vygotsky, 1978).

1.2 Literature review

1.2.1 Psychological, biological, social, and cultural perspectives on cancer

The issue of psychological distress in cancer patients is well tested and documented, with research suggesting more than a third of those experiencing the disease reach clinically significant levels of distress (Carlson et al., 2004; Mitchell et al., 2011), and this risk increases if a patient experiences a recurrence of the disease (NICE, 2004). Studies also suggest 58% of those diagnosed feel their emotional needs are not attended to in the same way as their physical ones (Macmillan Cancer Support, 2006). However, there are similarities between depression and the somatic symptoms of cancer and its treatments, which can make it an unrecognized or untreated comorbidity (Pinto-Gouveia et al., 2013). Hormonal medication can have a direct biological effect on emotional balance, especially in breast cancer patients where a reduction in oestrogen can result in hot flushes, night sweats, fatigue, and weight gain (Glaus et al., 2006). There is conflicting evidence about whether depression in such patients is caused by a reduction in the hormone itself or by the psychosocial factors resulting from its side effects, however, there is little doubt that living with hot flushes, sweats or an early menopause caused by chemotherapy, can overwhelm a patient’s coping strategies (Fann et al., 2008). Rapid cancer progression and increased pain is also associated with greater psychological distress and symptoms of depression (Spiegel et al., 1994). Overall, research suggests the physical and psychological effects of cancer lead to significantly lower levels of quality of life and wellbeing than that seen in healthy participants (Pinto-Gouveia et al., 2013).

The NHS England Long Term Plan has recently incorporated a new ‘quality of life’ metric in its cancer dashboard, to measure the psychological and emotional needs of those affected by the disease (NHS England, 2020) and this data may help future researchers better understand how a patient’s wellbeing is impacted after a diagnosis and what psychological support is offered, accepted and useful. In the meantime, it’s important to recognize the broader societal, cultural, and systemic background to cancer that can influence how individuals feel about being diagnosed and living with the disease.

The current discourse around cancer can be traced back fifty years to President Nixon’s launch of his ‘War on Cancer’. Tackling the disease became an American crusade and military metaphors around oncology spread, becoming so firmly ingrained within Western culture, that clinicians are still described as ‘frontline staff’, who are ‘battling’ to help ‘brave’ patients ‘soldier’ on. Penson et al., (2004) suggest this language can give patients and doctors meaning and a shared vision. Others argue it creates an unhelpful ‘win-lose’ situation, a false dichotomy. Periyakoil, writing about palliative care, suggests these metaphors encourage a patient to feel obliged to fight to the end, with a refusal of treatment seen as shameful or cowardly, a retreat from the ‘battleground’ (Periyakoil, 2008). In a Macmillan Cancer Support poll of 2,000 patients, those living with cancer said the words ‘war’, ‘battle’ and ‘victim’ were inappropriate, disempowering and isolating. More than a third (35%) said they never spoke about their fears of dying because of the pressure of being seen to ‘fight’. More than a quarter (28%) said they felt guilty if they couldn’t stay positive about the disease. The charity said the inability of patients to be honest about their fears, prevented many from accessing psychological help and it called for a cultural change, so patients no longer felt compelled to put on a ‘brave face’ (Macmillan Cancer Support, 2019b).

The ‘survivor’ identity in illnesses such as breast cancer, can often lead to feelings of shame and self-criticism, with cultural definitions of survivorship sometimes conflicting with individuals’ own lived experience of the disease and negatively impacting their perceptions of how they are coping (Kaiser, 2008; Taylor, et al., 1984). Research into individuals with breast cancer suggest a positive and significant relationship between body dissatisfaction, illness-related shame, and depression (Trindade, et al., 2018). Shame can be a painful response to loss of attractiveness, and/or the perception of social rejection, which increases vulnerability to mental health issues, and produces non-adaptive responses such as withdrawal, avoidance, and submission (Gilbert & Procter, 2006). Studies in a general population suggest a focus on compassion can help reduce self-critical thinking, depression, rumination, anxiety, the suppression of thoughts and neurotic perfectionism (Neff et al., 2007). Further research in those with breast cancer, suggests compassion-focused meditation practice can reduce levels of cortisol, increase heart-rate variability, and influence immune and behavioural responses, producing both psychological and physiological benefits (Wahl et al., 2018).

1.2.2 Defining rumination and self-compassion

Rumination and self-compassion are the two variables which have the most evidence in recent literature as mindfulness mediators on depression, according to a review (van der Velden et al., 2015). The constructs of rumination and self-compassion have also been shown to change positively after mindfulness-based interventions which integrate cognitive therapy principles (Gilbert & Procter, 2006;

Segal et al., 2002) and this section will explore how these concepts are defined and examined in the current literature.

Intrusive negative thoughts can contribute to depression in those with cancer, however it is the process of attending to them repeatedly, which is defined as rumination (Steiner et al., 2014). Studies suggest that rumination is not a unitary dysfunctional concept and can have an adaptive subcomponent (Cristea et al, 2012). *Brooding* rumination is thought to be excessive and non-productive; *depressive* rumination is characterised as a focus on one's feelings of sadness; and *reflective* rumination or pondering is thought to be more purposeful and problem-solving (Treynor et al, 2003). However, although reflection was initially seen as adaptive (Raes & Hermans, 2008), more recent studies suggest it can also be positively associated with depression (Pössel & Pittard, 2019), perhaps because it can lead to short-term negative affect if no active coping is involved while reflecting on negative experiences (Brown et al., 2019). Acceptance may be more useful in impacting anxiety and negative emotions in those with cancer, than reflective pondering (Cristea et al., 2012).

Compassion can be described as a motivation to care and be cared for, by developing skills such as an empathic understanding and an accepting, non-judgemental approach to suffering, which promotes positive affect and powerfully impacts on negative affect, reducing stress-linked immune and behavioural responses (Gilbert, 2017). The threat, or self-protection system activates the fight, flight, and freeze stress response through the arousal of the hypothalamic-pituitary-adrenal (HPA) axis and the stimulation of the sympathetic nervous system (Gilbert, 2015). While a high-threat focus is initially helpful for reactive problem-solving, an over-active threat system can lead to self-criticism and rumination, which increases the potential for psychopathology and can undermine morale (Brown et al., 2019). Compassionate behaviour can facilitate and activate the resting, or soothe system, activating the parasympathetic nervous system, with an associated rise in hormones such as endorphins and oxytocin, which in turn, can suppress the threat and drive response (Gilbert, 2017).

Self-compassion is defined as a caring and kind attitude towards the self, which requires the ability to give and receive compassion, while also allowing the regulation of one's own emotions by self-soothing (Hermanto et al., 2017). Kristen Neff believes this self-compassion has three aspects; *self-kindness*, a gentle and supportive understanding of the self; *perceptions of common humanity*, an awareness of the universality of suffering and *mindfulness*, a balanced openness to experiences, with their respective opposites being self-judgment, isolation, and overidentification (2012). This form of mindfulness refers to a non-judgemental perspective on an individual's suffering and negative experience, holding both mental and physical pain in balanced equanimity, rather than trying to avoid them (Svendsen et al., 2016). Self-compassionate people are said to ruminate less, perhaps because they are aware of, and can accept, perceived imperfections with kindness (Neff, 2003).

Research into the relationship between rumination and self-compassion among students, suggested that brooding was a unique mediator between self-compassion and depression, with high levels of self-compassion reducing unproductive and repetitive negative thinking (Raes, 2010). A more recent study suggested it mediated the relationship between self-compassion, anxiety, and depression in breast cancer patients (Brown et al., 2019) and a meta-analysis of compassion-based interventions drawn mainly from a non-clinical population, suggested self-compassion was linked to lower levels of depression and anxiety, with medium effects on both (Kirby et al., 2017).

While reducing rumination may help lower depressive thinking, it is the *active* nature of a self-compassionate approach which is thought to explain its effect (Svendsen et al., 2016). Neff (2011) said, "we can't heal what we can't feel" (p. 80) and it is this attendance to suffering which suggests an intentional act of self-kindness, of noticing and directing attention towards the feelings of hurt, rather than being caught up in brooding or depressive ruminative thinking which can be self-critical and judgmental. Being a “wise observer” enables one to compassionately work on thoughts and feelings, rather than being bound by the “felt reality” of them (Gilbert et al., 2011 p. 58).

1.2.3 Self-criticism, shame, and fear of compassion

The concept of self-criticism is mentioned in the literature as one of the main barriers to compassion, being strongly linked to depression and in one study, emerging as the best global predictor (Neff, 2003). Self-judgement or self-critique has been described as having two components; the inadequate self, with feelings of shortcomings or failure and the hated self, which can refer to feelings of disgust and shame (Gilbert & Irons, 2005). High self-critics with negative self-protective emotions can struggle with the concept of self-compassion, finding self-warmth and self-acceptance difficult (Gilbert & Procter, 2006).

Gilbert (2010) suggests shame recruits negative, threat-based emotions and cognitions and involves an evaluative component, both externally and internally. Those who feel shame may see themselves in the eyes of others as being flawed, inadequate or failing and thus believe they will be hurt or rejected; internally they may also believe this of themselves, leading to judgmental and self-attacking thoughts. A meta-analysis examining social-evaluative threats which induce self-blame and shame suggests that emotionally, this can produce feelings of anger, disgust, and self-contempt; behaviourally, it can result in avoidance or withdrawal and physiologically, it can activate the sympathetic nervous systems and the HPA axis, triggering the body’s stress response systems, affecting the heart rate and cortisol levels (Dickerson & Kemeny, 2004).

Self-criticism and shame can be present during a severe illness such as cancer (Kaiser, 2008; Taylor et al., 1984) and self-critical judgement is shown to correlate with depression in cancer patients, with higher levels of self-compassion associated with better psychological functioning (Pinto-Gouveia et al., 2013). Losing a breast or losing hair can provoke feelings of shame (Hefferon et al., 2010) with negative thoughts and feelings about one's body image leading to dissatisfaction and distress (Przezdziecki et al., 2013). Some cancer patients may feel self-blame about the cause of their cancer, leading to a negative perception of the self and poorer mental health (Phelan et al., 2013).

It is important to note that a harsh judgement of the self is not just about feeling negative or having an absence of compassion; those who are self-critical can also have a *fear* of affiliative emotions, including kindness (Gilbert et al., 2011). Gilbert's Compassion Focused Therapy approach (2009) suggests that self-criticism is a complex and adaptive evolutionary process, which is often attached to self-identity and safety strategies, built up, maintained, and stimulated in the presence of threat (Gilbert, 2009; Longe et al., 2010). Letting go of self-criticism can feel frightening and high self-critics may actively resist engaging in experiences which encourage reassurance and compassion, preferring instead to focus on self-esteem and striving for achievement (Neff & Vonk, 2009).

Research suggests the development of self-compassion may have an attachment-base (Gilbert, 2005; Neff & McGehee, 2010). Those with an attachment-secure foundation report higher levels of compassionate feelings than those with attachment anxiety or avoidance, as individuals who have faced early trauma or aversive backgrounds may not have experienced a feeling of safety or secure attachment that comes from being soothed (Mikulincer & Shaver, 2005). Bonding and trust stimulate oxytocin which plays an important role in the regulation of the HPA axis, helping to mediate the body's stress response, however if there have been few experiences of this, then the soothing system may not have been developed and individuals may find accessing it, threatening (Bowlby, 1979; Gilbert, 2010). If the attachment system has shut down, reactivating it may bring back emotions and feelings which block recovery, especially for those with high shame and self-criticism (Gilbert & Andrews, 1998).

Research by Gilbert et al., (2011) linking the fear of receiving compassion from others or showing it to the self with attachment difficulties, self-criticism, and other mental health problems, has been confirmed in a meta-analysis examining fears of compassion and mental health (Kirby et al., 2019). Compassion from others can trigger feelings of grief if someone has been rejected previously; avoidant individuals may view support-seeking by themselves and others as a weakness and deserving of contempt, and compassion itself might be confused with submissiveness (Gilbert, 2020). Gilbert et al., (2011) suggest this fear of compassion may be addressed by accessing different forms of therapy and developing alternative ways of interpersonal safeness, which encourage a feeling of kindness from others, towards others and towards the self, and they urge individuals to explore the value of mindfulness interventions focusing on kindness.

1.2.4 Mindfulness-based interventions in health psychology

Mindfulness is a concept which can be difficult to define and quantify (Grossman, 2008; Hofmann et al., 2011) and its many adaptations and approaches makes scientific enquiry a complicated procedure. One definition suggests it encourages the individual to shift their perspective on thoughts, emotions, and sensations, so that rather than ruminating over them, they are held in a non-judgemental, moment-to-moment place, encouraging awareness, equanimity and openness through intention, attention, and attitude (Shapiro & Carlson, 2009; Shapiro et al., 2006).

This idea of non-judgemental self-kindness is at the heart of most mindfulness-based interventions (MBIs) and is empirically associated with positive outcomes in those with depressive symptoms, both immediately after the intervention and at 15-month follow-up (Kuyken et al., 2015). The most widely researched of these interventions is Jon Kabat-Zinn's Mindfulness-Based Stress Reduction (MBSR, Kabat-Zinn, 1984), a structured eight-week group programme focusing on 2-2.5-hour sessions of meditation, discussion, gentle yoga, and body scans, with additional home practise and an all-day retreat. Initial research suggested positive effects in conditions such as generalised anxiety disorder, panic, chronic pain, anxiety, and depression (Kabat-Zinn, 1991). MBSR was subsequently adapted to treat different conditions, such as Mindfulness-Based Cognitive Therapy (MBCT) which takes most of the MBSR curriculum, combining it with techniques from cognitive behavioural therapy (Teasdale et al., 1995). Studies suggest efficacy in managing the risk of relapse in depression compared to treatment as usual (Piet & Hougaard, 2011; Segal et al., 2002; Teasdale et al., 2000) and it has been recommended by NICE as a priority treatment for depression since 2004 (NICE, 2004, 2016).

The experience of holding mental and physical pain in 'balanced awareness', being in the 'here and now', neither looking to the past, nor projecting ahead, and developing an attitude of 'loving-kindness' (Neff, 2003) feels particularly salient to those living with cancer, who may present with emotion regulation difficulties, low mood, ruminative thinking, and low levels of self-compassion and motivation (Baer, 2014). Several programmes specifically designed for cancer have developed out of MBSR and MBCT, two of which are Mindfulness-Based Cancer Recovery (MBCR; Carlson et al., 2011) and Mindfulness-Based Cognitive Therapy for Cancer (MBCT-Ca; Bartley, 2012). Both are eight-week courses with group classes using mindful movement, imagery, and cognitive coping strategies to deal with common cancer experiences, such as a loss of control, the fear of recurrence and managing uncertainty.

Most empirical literature on MBIs in those living with cancer examines the efficacy of MBSR or MBCT, with symptom reduction, biomarkers and psychological outcomes being widely studied. Research determining the efficacy of MBSR on breast cancer survivors found an increased ability to cope, manage and find meaning (Kenne Sarenmalm et al., 2017) and another suggested a reduction in fear of recurrence, stress, and anxiety (Lengacher et al., 2012). Systematic reviews and meta-analyses of MBSR and MBCT in this population also suggest beneficial effects in depression, anxiety, and stress, together with an improvement in quality of life (Haller et al., 2017; Huang et al., 2015). More recent systematic reviews and meta-analyses of RCTs in a broader cancer cohort, suggest improvements in reducing psychological distress (Cillessen et al., 2019) and reductions in anxiety, with short-to medium-term benefits regardless of type of cancer, severity, or phase of treatment (Oberoi et al., 2020).

Any intervention that has the potential of relieving psychological distress, also risks adverse effects (Foulkes, 2010) and it is important to note the small, but growing number of studies, reporting negative effects of mindfulness. One study with 294 student participants suggested those who listened to a 15-minute audio meditation and then completed word recall exercises, reported more critical words than those who engaged in mind-wandering exercises (Wilson et al., 2015). A smaller, qualitative study suggested that although participants reported positive effects after an MBI, a quarter reported problems in their mindfulness practice, including an exacerbation of mental health issues and troubling experiences of self, including psychosis, dissociation, and suicidal thoughts (Lomas et al., 2015). There is also small-scale evidence suggesting meditation may induce psychotic episodes (Shonin et al., 2014), however, the authors of this review paper suggest most studies were uncontrolled and based on modalities of ‘meditation’, rather than mindfulness itself. A paper appraising the critical evidence behind reported adverse effects, suggests a potential lack of understanding of the nuances of mindfulness among some teachers, which may lead to poor teaching and therefore pose a greater risk to participants (Van Gordon et al., 2017). Overall, adverse events are reported in 0-10% of participants during MBIs, which is no more common than control groups and none of the adverse events was directly attributable to the MBI itself (Baer et al., 2019).

However, mindfulness-based interventions should not be seen as a cure-all for the growing numbers of people who are experiencing psychological difficulties while living with cancer. In 2015, the first 'Mindful Nation UK Report' was produced by the Mindfulness All Party Parliamentary Group (MAPPG) and although it highlighted potential benefits of mindfulness within health settings, it also warned that with more than five hundred peer-reviewed scientific papers on the topic published every year, its popularity risked running ahead of the evidence (MAPPG, 2015). Research psychologists from the Oxford Mindfulness Centre urge rigour and a healthy scepticism when examining any promising interventions and suggest researchers test and disseminate mindfulness interventions in a range of settings with diverse individuals, something that is rarely done (Gjelsvik et al., 2018).

1.2.5 Methodological issues in quantitative research

A Cochrane review of MBSR interventions in breast cancer survivors concluded that anxiety, depression, and sleep improved both at the end of the intervention and six months later (Schell et al., 2019). However, the authors of this study note limitations in quantitative research with the possibility of a high risk of performance and detection bias. This methodological concern is echoed elsewhere, with another systematic review of MBSR in cancer care, highlighting the diversity in study design and intervention (Shennan et al., 2011).

A further systematic review of MBSR/MBCT in cancer cohorts suggested most interventions were poorly defined with too much variability, noting the protocol often changed during treatment, that there was a lack of participant adherence during home practise, unexplained missing data and often, information was gathered sometime after the MBI had been delivered (Shaw et al., 2018). A research article reviewing 124 MBI RCTs in healthcare concluded that almost 90%

reported positive results and the authors suggest this may be due to effect sizes being over-stated, selective outcome reporting, ‘data dredging’ and overall reporting bias (Coronado-Montoya et al., 2016).

Few studies say where the MBI training took place. The only known UK trial in a community-based cancer-care setting was at Breast Cancer Haven, a charity day centre providing free psychological care for breast cancer patients. This randomised, wait-list controlled study suggested improvements in mood, endocrine-related quality of life and well-being more than three months after MBSR treatment, compared to standard care (Hoffman et al., 2012a). While this was a unique study delivering a free intervention away from the hospital, a key limitation included the delivery of the intervention by the researcher herself, possibly creating tension and bias.

There are fewer quantitative studies on interventions specifically tailored to a cancer population, for example MBCR and/or MBCT-Ca. The first study into MBCR noted a significant improvement in mood states and symptoms of stress compared to a control group (Speca et al., 2000) with similar benefits noted in follow-up studies at six and twelve months (Carlson et al., 2007). In a study comparing MBCR to Supportive Expressive Therapy (SET) with 252 women with breast cancer, improvements in stress symptoms were noted, which were maintained a year later (Carlson et al., 2016). However, contact was lost from half the participants, potentially exaggerating results and this is a limitation of many large, RCT trials. One MBCR and wait-list controlled study with 135 participants noted positive effects on rumination and worry, but there was a 35% drop-out in the MBCR group, double that of the waitlist, potentially influencing results (Labelle et al., 2014).

Another study with 271 breast cancer participants suggested they improved significantly over a SET group on mood disturbance, stress symptoms and social support, however once again, more than a third failed to complete pre- and post-intervention questionnaires and some participants did not finish the course

(Schellekens et al., 2016). None of these studies investigates why the participants dropped out, potentially biasing results towards those who were more positive and self-motivated.

Hanley et al., (2012) suggest that in Counselling Psychology, holistic processes can be hard to monitor with quantitative research as they require a more complex, nuanced way of accessing the ‘truth’. Mindfulness encourages a recognition of the co-existence of struggle and growth, a complexity which may be hard to encapsulate for those looking for statistically significant ‘positive’ results. Also, as discussed earlier, those with cancer can be defined as a fighter, a sufferer, a victim, or a patient; potentially reductive terms which can create critical self-judgment, and which prevent many from accessing psychological help (Macmillan Cancer Support, 2019b). Quantitative approaches may be yet another reductive process, potentially quietening the richness of the individual’s voice.

Qualitative studies in mindfulness and cancer care are less researched. A review documenting thirteen research papers and conference abstracts, noted two qualitative papers and called for further research into the mechanisms and processes of how mindfulness unfolds for an individual (Shennan et al., 2011). Further qualitative studies since suggest strengths and weaknesses.

1.2.6 Methodological issues in qualitative research

A systematic review of qualitative evidence on mindfulness in cancer care identified just six studies (Tate et al., 2017), most of which reported benefits in reduced stress and anxiety, and greater skills in acceptance and coping (Brotto & Heiman, 2007; Dobkin, 2008; Hoffman et al., 2012b; Mackenzie et al., 2007). There are several methodological issues, however. One was a small pilot study and the full MBSR programme was not completed (Brotto & Heiman, 2007). A mixed methods pilot study with men with prostate cancer suggested promise for reducing anxiety, avoidance, and fear of recurrence, but the mean time since diagnosis (7.7 years) limited findings (Chambers et al., 2011, 2017).

The remaining studies had other limitations. In one, participants (*N* = 9) had practised MBIs for years before the research intervention took place (Mackenzie et al., 2007). A low sample (*N* = 18), high drop-out and lack of adherence to the programme at home was an issue in a thematic analysis study of another modified MBSR programme (Kvillemo & Bränström, 2011). As with much of the quantitative research, no explanation of drop-out or lack of adherence to the original protocol is given, potentially biasing the results.

A UK study used part of the breast cancer cohort from the Hoffman et al. (2012a) quantitative research above, for a thematic analysis into mindfulness-based stress reduction (Hoffman et al., 2012b) with individuals reporting a decline in stress, anxiety, and panic. Creating space, improved communications and being more mindful and at peace were among the other reported benefits. Data was collected through a short questionnaire with one closed and four open questions, some participants were not asked one of the questions and the intervention was once again, conducted by the researcher, which might have influenced responses. The authors noted these limitations, suggesting that semi-structured interviews are more likely to have encapsulated the depth and breadth of experience (Hoffman et al., 2012b).

The lack of complexity and nuance may also be an issue for qualitative studies using focus groups (Dobkin, 2008; Mackenzie et al., 2007; Schellekens et al., 2015). While focus groups enable statements to be tested and developed, potentially generating rich data about meaning, they may not be appropriate to sensitive subject matters (Willig, 2013). As the experience of cancer can be intense and personal, interviews may best be conducted one-to-one, using open-ended or semi-structured questions. Focus groups may illicit extreme emotion and might be more suitable with those not directly experiencing the disease, for example nurses, carers, or partners. A mixed methods feasibility study for MBSR in an NHS setting used questionnaires and qualitative data from semi-structured interviews with women with metastatic breast cancer and focus group data from oncology nurses (Eyles et al., 2014). This mixed methods design and methodology was a strength of the study, however the authors noted difficulties in recruitment and adherence to the MBSR programme and suggested that an adaptation of the intervention for those with cancer, might have been more worthwhile.

Mindfulness-based approaches can appear to be low-cost and easily implemented interventions, potentially helping those individuals suffering psychological distress, who are not well served by current healthcare provision, however researchers should exercise caution in how results are reported, avoiding caveats or ‘spin’ (Coronado-Montoya et al., 2016). One recent review into potential harm in mindfulness-based interventions, suggests researchers examine whether group averages conceal deterioration in individuals (Baer et al., 2019) and the authors suggest using the Reliable Change Index (RCI; Jacobson & Truax, 1991), which measures clinically significant positive and negative change in each participant.

1.2.7 The pandemic and cancer

It’s important to note the impact of the coronavirus pandemic on those living with cancer. Cancer already presents psychological challenges because of the potential distress caused by diagnosis, treatment, and the uncertainty of outcome, but a recent study into the impact of the first pandemic peak in May 2020 on Iranian women with breast cancer, suggests it increased their emotional and cognitive vulnerability (Choobin et al., 2021). Most published studies were conducted earlier in the spring of 2020, when there were fewer active COVID-19 cases. One such study into psychological distress in 72 participants with cancer and 45 healthy controls in Hong Kong suggested cancer patients reported greater catastrophizing and health anxiety, however they also reported less distress in comparison to the healthy controls and perceived significantly fewer negative consequences from the virus itself. The authors concluded that those experiencing cancer may be better prepared emotionally to respond to the pandemic, although they note the research took place before the virus really took hold (Ng et al., 2020).

Research with 260 cancer patients in Poland suggested cancer patients were faced with an unenviable dilemma when COVID-19 began to spread; stay at home and risk tumour progression or visit hospital, potentially increasing the risk of catching the virus (Ciążyńska et al., 2020). This study reported that one in five were already considering abandoning chemotherapy and half felt more isolated, as family and friends could not participate in the process of diagnosis and treatment, significantly impacting their quality of life and the authors suggest COVID-19 may have contributed additional psychological distress for cancer patients with the sense of isolation and a change in treatment options.

There is little research into the psychological effects of the virus on UK cancer patients, using the patients themselves. One study with 94 UK healthcare professionals working in the field of psycho-oncology, conducted in May and June 2020 when many lockdown measures were in place, suggested patients’ treatment plans were altered, with an increase in social isolation and lack of face-to-face monitoring, which led to some staff feeling they could not deliver the same standard of care. However, the authors also noted the creative and flexible ways that psychological care was being delivered during the pandemic and they called for further studies to better understand how this may benefit those living with and beyond cancer (Archer et al., 2020).

1.3 Summary of literature and conclusions

This literature review has evaluated the current evidence on MBIs as an intervention which can improve emotion regulation for those with cancer, while also examining the controversies over some of the methodological shortcomings. The research suggests rumination, self-criticism and fears of compassion are important concepts to examine in the context of an MBI and this review has moved towards a general definition of these, involving psychological, biological, neurological, social, and cultural factors, as well as cognitive and affective perspectives in the context of cancer.

A stated aim of MBIs and perhaps a key to its efficacy, is the process of change in self-compassion, consistently associated with positive outcomes (Kuyken et al., 2015). This literature review examined the research into how mindfulness might lower harsh, self-critical thoughts by replacing them with a more self-compassionate, soothing approach, enhancing wellbeing, and allowing for a greater capacity to manage stress, anxiety, and depression (Costa & Pinto-Gouveia, 2010; Gilbert & Irons, 2005). While a relatively new area, especially in cancer, the literature around self-compassion did emerge as a promising area for research. A poster presentation of a preliminary study, conducted at Breast Cancer Haven in London noted a reduction in stress, anxiety and depression and a cultivation of self-compassion in those with the disease (Hoffman et al., n.d.).

However, only one published study seems to explore this concept qualitatively in MBIs in those with cancer, the sample size was small (*N* = 10) predominantly female, and all interviews were conducted more than a month after the intervention. This study pointed to the almost exclusive reliance on quantitative studies in the development of compassion in cancer after mindfulness, suggesting the *processes* involved are unclear and largely unstudied and the author suggested further research into the shifts in perceptions of self (L’Estrange et al., 2016).

Elaine Kasket urges researchers to be careful before overlooking or rubbishing the value of quantitative research (Kasket, as cited in Galbraith, 2017), however there is an inherent risk of objectifying health and illness, thus bypassing, rather than prioritising the construction of the individual's experience, if they are not allowed to express those processes and shifts in their understanding of themselves (Radley, 1999). Participants are often recruited from oncology departments rather than community settings and referred to as 'patients' rather than 'individuals', risking further 'medicalization' (Conrad, 2007). Empowering individuals with cancer to express themselves away from a hospital setting, may give them back the voice that is sometimes lost, both in their treatment and in many studies.

1.4 Research justification

1.4.1 Aims

This research aims to address the gaps in research by asking:

1. What is the relationship between mental adjustment to cancer, rumination, and compassion in those with cancer, both before and after an eight-week MBI specifically designed for those with the disease?
2. How does the broader context; for example, the stigma associated with the disease and any societal pressure to 'fight' it, play into the concepts of ruminative worry and critical self-judgement?
3. If there is a shift in coping, rumination and compassion following the mindfulness course, how are processes and mechanisms interpreted and conceptualised?

The aims of this study are to move beyond a focus on outcomes to that of examining meaning and moments, emotional shifts, and changes. This necessitates a mixed methods approach, which reflects Counselling Psychology's postmodern, pluralistic, philosophical, and humanistic ethos (Ponterotto, 2005). If those with cancer feel a 'loss of self', both in the experience of illness (Charmaz, 1983) and in much of the hospital-based, quantitative research which aims to help them, this research aims to address that, by prioritising the voice of the individual.

1.4.2 Rationale

As this literature review has shown, more people than ever are living with cancer, many are struggling with the emotional effects of it, yet few get the psychological help to cope. Counselling Psychology's mission is to advance the profession by promoting wellbeing, and its vision is to lead and influence the design and delivery of innovative policies and services (BPS, 2018 p. 4). However, there are gaps in the existing research for a study examining one of these innovative interventions; mindfulness and its potential to change ruminative and negative thinking and fears of compassion, in those living with and beyond cancer.

This is best explored with a study in a UK-based cancer care support centre, which examines the experience of those living with the illness, following a disease-specific, mindfulness-based intervention. A mixed methods approach, drawing on the benefits of both quantitative and qualitative approaches, will allow data from pre- and post-intervention questionnaires to inform subsequent semi-structured interviews, in an explanatory, sequential design, often most appropriate in healthcare settings (Ivankova, 2017). Qualitative analysis takes account of the uniqueness of an individual's experience in understanding the process of any change, while also searching for unifying themes of those taking part.

1.4.3 Hypothesis

The online survey, delivered pre- and post-intervention, measures rumination and fears of compassion as well as attitudes and perceptions towards the disease itself, with the hypothesis tentatively suggesting a potential relationship between factors and a change in emotional affect between the two time periods.

The strength of the qualitative part of this study allows the research to move beyond the framework of the original hypothesis to explore unexpected patterns of experience and/or behaviour.

1.4.4 Implications for Counselling Psychology

Counselling Psychology research is at a watershed moment. An article by the Editor of Therapy Today suggests politics and the NHS funding context still drive much of the quantitative, RCT-based healthcare research (Jackson, 2018). It quotes the ideas of Mick Cooper and John McLeod, who argue for a more pluralistic approach, testing and evaluating interventions within organisations and hearing the thoughts of those who use them (Cooper, 2012; Cooper & McLeod, 2007).

In exploring the experience of those with cancer following a disease-specific MBI in a community setting, this study endorses that approach. The research attempts to contribute to the understanding of the experience of those living with and beyond the disease, to see whether the intervention can shift their perceptions of themselves and their illness, while also exploring the concepts of rumination, self-criticism, and fears of compassion, to see how individuals make sense of any change. The research aims to inform clinical practice and policymaking in mindfulness, compassion, and cancer, while also helping those living with and beyond the disease to better understand what an MBI experience might be like. It attempts to answer the questions: what is compassion and how is it conceptualised by those taking part? How does self-criticism and self-compassion influence one’s perception of living with the disease and how might it shift during and after an MBI? How difficult did participants find mindfulness? Which part of it was harder than others? What were they surprised by, moved by, upset by? Would they recommend it to others? If so, when in the cancer treatment trajectory, should individuals try it? What made the difference and enabled the shift? How might you bring mindfulness into the everyday? Has it helped in the context of COVID-19 and if so, how? The existing theories and research use a ‘top down’ approach. This research attempts to inform and perhaps effect policy change, by using a different approach and prioritising the voice and experience of the individual.

Chapter Two: Research Methodology and Procedures

2.1 Methodological integrity and transparency

In this chapter, I outline the rationale of using mixed methods to answer the research question, the benefits, and tensions of such an approach and my epistemological positioning, before detailing quality markers and procedures.

‘Mixed methods’ as an identifying term to describe single studies combining both quantitative and qualitative approaches, is relatively new (Tashakkori & Creswell, 2008), but the process of combining data to better understand phenomena, is not. Carl Rogers was one of the first to advocate for multiple methodological approaches rather than just relying on positivism alone (Rogers, 1965, 1985) and mixed methods became popular in the social sciences in the late 1960s as a way of confirming, or triangulating results (Leech & Onwuegbuzie, 2007). Quantitative methods are widely used in Counselling Psychology to test hypotheses in large groups, known as the ‘generalizability theory’ (Brennan, 2001) however they cannot capture the richness and diversity of human experience in the same way as qualitative methods (Willig & Stainton-Rogers, 2017). Combining the two gives researchers a way of harnessing the strengths of both approaches (Tashakkori & Teddlie, 2010); using quantitative methods to assess frequencies, magnitude and change in concepts and constructs, and qualitative to explore the process, context and meaning of that change in greater depth.

While mixed methods are becoming more popular, a best practice guide into their use in health sciences suggest researchers provide a clear rationale of why they are being used, by articulating the benefits and by making clear how mixed methods can bring an innovative approach to the area under review (Creswell et al., 2011). The research question in this study asks how individuals with cancer adjust to their disease, and experience rumination and fears of compassion after a cancer-specific mindfulness-based intervention (MBI) in a community cancer support centre.

Quantitative measures can evaluate the effectiveness of this MBI, using statistical analysis to examine whether participants report a change, but they cannot capture how individuals perceive any shift in thoughts, feelings, sensations, and behaviours and what meaning they attach to this process. For that, qualitative measures are needed. Connecting and integrating both sets of data can “better understand why or how something happened from the perspective of clients and participants” (Bartholomew & Lockard, 2018, p. 1699). Valuing the interplay between symptom change and lived experience can add to and enhance the clinical knowledge around the possible risks and benefits of an MBI and “provide crucial insight into aspects such as the feasibility or acceptability of a particular intervention” (Midgley et al., 2014, p. 131).

This approach also reflects Counselling Psychology’s postmodern, pluralistic, philosophical, and humanistic ethos (Ponterotto, 2005). Yardley and Bishop suggest a pragmatism in recognizing that mixed methods research is advantageous, as well as necessary and important “to gain a complete understanding of humans” (Yardley & Bishop as cited in Willig & Stainton-Rogers, 2017 p. 6). However, quantitative and qualitative approaches use different paradigms, aims and validation measures, and this study also explores the philosophical and practical tensions involved in mixed methods research.

2.2 Theoretical positioning and tensions

The philosophical lens for this study frames suffering as inevitable and intrinsic to life, a given in human existence which surpasses our knowledge of it

(Spiro, 1982). Compassion is derived from the Latin term ‘com’ and ‘pati’; meaning ‘to suffer with’. *Self*-compassion is a deep awareness of this suffering in oneself while recognizing that pain is also part of a common humanity (Gilbert, 2009). While everyone actively perceives and creates their own meanings in response to difficult circumstances and events (Yalom, 1980), there is a universality in the suffering itself. Painful experiences are both unique and part of being human, as is the concept of self-compassion, the “compassion turned inward”, that is used to manage it (Neff, 2012).

2.2.1 Ontology and the ‘reality’ of cancer

Ontologically, this study sees an individual with cancer as a ‘person-in-context’, recognizing that everyone’s ‘being-in-the-world’ is always perspectival, temporal and in relation to something (Heidegger, 1962). While ‘ontological realism’ recognizes a degree of stable, enduring reality, this is separate from our thoughts, opinions, theories, and constructions of it (Willig, 2016). For example, I assume cancer has an independent status as a bodily process which remains separate to what we know about it; the disease is ‘real’, as is the participant’s experience of it (Willig, 2013). Cancer is a mechanism in nature when cells metabolize too quickly. There may be causal reasons for it or not; our activity may generate it, or it may be independent of it. Although the *existence* of cancer is real, our *knowledge* of the disease and its causality is fluid.

How we perceive and react to cancer can also change based on where we are situated, as our knowledge of it can be affected by prior events and influenced by new ones. This sits with a social constructivist approach which suggests our reality, or meaning, is actively constructed using our culture, experience, beliefs, and values. Critical realism sits within this ontological understanding (Bhaskar, 1975, 1989, 2011) as it assumes that research data does not hold a mirror to the world to reflect reality, but rather, needs to be interpreted with attention to the individual’s context and language, as well as the position of the researcher, their lived experience, biases and expectations, and the interaction between all of them (Schwandt, 1994).

2.2.2 Epistemology, or how we know what we know

While this study’s ontological position is founded in critical realism, so too is the epistemology. It emphasizes the impact of structures and contexts looking “beyond surface appearances, to search for the underlying processes that account for natural and social phenomena” (McEvoy & Richards, 2006 p. 418.) The goal of this research is to better understand these processes, rather than taking a positivist approach of trying to identify generalizable laws. My position also assumes my *erlebnis*, or lived experience, cannot be separated from the research itself; the relationship between the ‘knower’ (the participant) and the ‘would be knower’ (the researcher) is a dynamic one; both dialogic, resulting in deep insights, and transformative or dialectic (Ponterotto, 2005).

2.2.3 Pragmatism, pluralism, and paradigm wars

The question at the heart of this research, that is, the understanding of an adjustment to cancer, rumination, and fears of compassion in those with cancer and how it might shift after mindfulness, is privileged over the tools, or methods used to understand or answer it (Willig, 2013). This pragmatic approach is both productive and pluralist, going beyond a strict realism-relativism divide, to produce research which helps promote action and drive change (Cornish & Gillespie, 2009). Pragmatism is seen as one of the best philosophical bases for mixed methods studies, for as Teddlie and Tashakkori (2003) put it: “mixed methods research can answer research questions that the other methodologies cannot” (p. 14).

A pragmatic approach considers ‘what works’ and in this study, that means using diverse approaches to answer the question. Mixed methods are increasingly being used in healthcare (Klassen et al., 2012) and in cancer research, it is suggested that when the exploration of lived experience is added to the quantitative data, a study gains clinical efficacy, importance and significance, illuminating understanding while maximising the strengths of both approaches in a more holistic way, which best fits the needs of those with the disease (Kennedy & Hulbert-Williams, 2015, p. 508).

While this pragmatic and pluralist approach seems the right fit, this study also recognizes the philosophical tensions involved in mixing methods, due to the different epistemological and ontological assumptions which underpin them. Quantitative measures are often rooted in a belief in a singular reality which can be objectively captured, analysed, and measured (Ponterotto, 2005), whereas qualitative approaches are more aligned to a belief in a world full of multiple, subjective realities, based on context. Some suggest the two are incompatible and mixing them cannot work (Smith & Heshusius, 1986). Others argue these ‘paradigm wars’ are themselves superficial, as quantitative approaches are not always objective, while qualitative procedures are not always subjective (Bryman, 2006). Indeed, Willig (2016) argues that most qualitative research is based on “ontological realism, together with epistemological relativism” (p. 33) and Bryman (2006) argues for research that embraces a ‘paradigm peace’ and a ‘methodological eclecticism’, uniting approaches regardless of their “supposed philosophical presupposition” (p. 124).

The methodological eclecticism in this study views the research question in the quantitative part of this study from a post-positivist standpoint, seeking to find answers that enable prediction (Ponterotto, 2005), while understanding there is no objective reality. Thus, Part One is numerical, specific and emphasises scope, while Part Two examines depth and richness. Integrating both allows for the distinctiveness and creative tensions of the different approaches and methods, to be acknowledged and embraced (Mason, 2010).

2.3 Methodology and study design

This study uses a mixed-methods, sequential explanatory design. Quantitative measures examine mental adjustment to cancer, rumination, and fears of compassion pre- and post a mindfulness course. The study then moves beyond outcomes to a qualitative focus on participants' meaning of any shifts in these concepts. This study aims to address any 'loss of self' in the hospital experience (Charmaz, 1983) by examining MBIs running in several community-based, Maggie's Cancer Care Centres. It also prioritises the sense-making experience of the individual by weighting the emphasis towards the qualitative data, in an unequal, mixed methods approach (Morgan, 1998), so-called 'quan-QUAL' (Hanson, et al., 2005).

The sequential explanatory design of this mixed methods study means the qualitative data is used to "corroborate, refute, or augment" the earlier survey findings (Hanson, et al., 2005 p. 227). Thus, the methodology follows several steps (see Appendix 17a).

1. Pilot quantitative study distributed and returned
2. Pre-intervention questionnaire distributed to consenting participants
3. After eight-week course, post-intervention questionnaire distributed to same participants
4. Analysis of quantitative data, examining for change of symptoms
5. Participants identified from survey dataset for follow-up interviews
6. Screening calls for participants who consent to interview
7. Semi-structured interviews examining processes of coping/rumination/ compassion
8. Analysis of qualitative data
9. Integrating both sets of data in the writing up

This approach mixes a top-down deductive process with a bottom-up inductive process to “search for relationships between entities, the processes that underlie these relationships, and the context of these occurrences” (Teddlie & Tashakkori, 2003, p. 17). It is an iterative, cyclical approach to research which integrates the data, while remaining flexible and open to new, sometimes contradictory, findings.

This dynamic approach necessitates a reflexive stance. I have previously worked at Maggie’s as a trainee counselling psychologist and have lived with the disease myself. My motivation for the study was informed by my work with those with cancer, my own experience, and my desire to produce research with an implicit social justice agenda, which gives voice to a marginalised group (Braun et al., 2018). Reflexive Thematic Analysis (RTA) has been chosen as the study’s qualitative analytic approach, as it acknowledges my own perspective and position in representing these voices (Braun & Clarke, 2019). Thematic Analysis has many different approaches; using it reflexively means prioritising a flexible, organic, and recursive engagement with the data and acknowledging researcher subjectivity in the active creation of themes. The rationale for this over other approaches is explored below (see 2.6.2.1). Further details on the phases of TA, and the qualitative participants themselves, will be covered in the Analyses chapter.

2.4 Part One – quantitative methodology

A survey questionnaire was chosen to answer specific questions about adjustment to cancer or coping style, rumination, and fears of compassion. By distributing the survey before the mindfulness-based intervention and having the same participants complete it afterwards, any reported changes in scores could be analysed to examine perceived shifts. These findings could then be explored during Part Two of the study, keeping an open mind as to whether change would happen, in which direction it would go and whether participants would corroborate or contradict it.

Part One represents a nomothetic approach, which is sometimes criticised for focusing on a general population and missing out individual differences (Lamiell, 1981; Runyan, 1983). To make the study more robust, the Reliable Change Index (RCI; Jacobson & Truax, 1991) was used to investigate intra-individual change. The RCI computes the standard error of measurement and the standard error of difference scores to calculate reliable improvement or deterioration in each participant that is not likely due to chance, or an error of measurement (p <.05). This index presents a valid and visual view of clinical and meaningful change in a participant and is becoming a requirement in many high-impact journals (Britton, 2019). It can also be used for further participant selection (Zahra & Hedge, 2010) and in this study, was used to identify participants who had experienced significant and reliable change.

2.4.1 Measures

A pilot study, which included a series of demographic questions and a survey based on three validated scales, was distributed to mindfulness teachers and centre heads at Maggie’s, as well as several people with a cancer experience, to assess its suitability for individuals already undergoing a difficult experience (Kennedy & Hulbert-Williams, 2015). The feedback was positive, with suggestions of small changes in grammar and survey flow to increase understanding, and the finalised, pre-course questionnaire sent to participating centres before the interventions began.

All participating centres were running eight-week Mindfulness-Based Cognitive Therapy for Cancer courses (MBCT-Ca; Bartley, 2012) which were led by experienced and trained mindfulness teachers. The protocol consists of eight weekly sessions of around 2.5 hours including meditations, body scans, ‘pause’ exercises and noticing reactions to difficult or unpleasant experiences. The course embodies the approaches of MBCT and MBSR with a focus on suffering, practice, and presence. There is no yoga element and the cognitive model, introduced in week four, concentrates on distress in the cancer experience. The eight-week course includes a silent retreat day in week six and participants are also encouraged to practise mindful exercises at home and follow a CD of 30-minute meditations.

The three scales in the survey included: the Mental Adjustment to Cancer Scale (MACS; Watson et al., 1988), a 40-item, 4-point scale which was developed to understand the adjustment of patients in cancer treatment and was originally designed with five subscales, measuring fighting spirit, anxious preoccupation, avoidance, helpless-hopelessness, and fatalism. The Ruminative Responses Scale (RRS; Treynor et al., 2003) examines the presence of repetitive depressing, brooding, or reflective thoughts and is a 22-item, 4-point scale, assessing an individual’s cognitive coping style by finding meaning in ruminating, entangling with feelings, repeatedly paying attention to the symptoms, and/or trying to work out causes or consequences of emotion. The Fears of Compassion scale (FCS; Gilbert et al., 2011) was developed as a 20-item, 5-point scale for anxious and depressed patients for whom compassion brought avoidance and fear reactions (Gilbert, et al., 2011) and assesses whether participants report a fear of acknowledging kindness from others, expressing it to them and/or showing it towards themselves.

This phase was designed as a repeated measures test on a single sample, and those who consented and completed the pre-course questionnaire were advised they would be asked to complete it again at the end of the eight-week course.

2.4.2 Participants

2.4.2.1 Recruitment*.*

The study was first discussed with Maggie’s Clinical Lead Psychologist in Spring 2019. She acted as a ‘gatekeeper’, who was supportive of the research and could ‘open up’ the organization (Creswell & Plano Clark, 2017). Organisational consent was given in the summer of 2019, after conversations about how the data would be stored and used and the potential impact of the research, both on Maggie’s and on those taking part (Appendix 2). Although I had previously been on placement at a Maggie’s centre, I had no contact with it outside the scope of this research, to minimise any potential influence or conflicts. Initially, three London centres agreed to participate but it was decided, after discussions with my university supervisor, to extend the research to other UK centres to try to maximise geographical and sociocultural diversity and increase validity by opening the study to more participants.

2.4.2.2 Inclusion criteria.

The inclusion criteria, developed in accordance with the MBCT Implementation Resources for recruitment (Kuyken et al., 2012), included those between 25-85 years old, with a cancer diagnosis, who could speak and read English. The exclusion criteria included those experiencing an acute episode of depression or anxiety, or who had a mental health diagnosis, or who were addicted to alcohol or drugs and/or had an additional acute life crisis such as a recent bereavement.

2.4.2.3 Sample size.

The stated aim and objective of Stage One of this feasibility study was to investigate whether those who had chosen to participate in the MBCT-Ca course and consented to the pre- and post questionnaire, perceived any shifts in negative coping, rumination and fears of compassion. The numbers of those eligible was potentially limited by the inclusion and exclusion criteria, changes in disease trajectory affecting commitment (Curry et al., 2013) and self-selection, suggesting a potential for low statistical power and a small effect size (Kennedy & Hulbert-Williams, 2015). Numbers were also affected by the coronavirus pandemic, which led to courses being cancelled. Research recommends sample sizes of between 12 and 50 for a pilot or feasibility study (Julious, 2005; Sim & Lewis, 2012.) A similar mixed methods feasibility study examining the psycho-social impact of an MBI in those with metastatic breast cancer, had an N of 19, which was considered appropriate (Eyles et al., 2014).

2.4.2.4 Procedure.

Following full approval from the University Ethics Committee (see Appendix 1a), all centres running mindfulness courses were sent participant information guidance (see Appendix 9), which was later updated with a Quick Response (QR) code and link to the study (see Appendix 10). Laminated cards with the QR code were distributed to maximise accessibility on mobile devices, potentially increasing distribution. Centre heads and mindfulness teachers were not expected to recruit participants, however interested individuals were directed to the poster (see Appendix 3) and guidance.

2.4.3 Hypotheses

The combined data from the pre-post questionnaires aimed to answer the following:

a) Have participants’ adjustment to cancer, rumination and fears of compassion changed pre- and post the mindfulness course and if so, how?

b) Is there a relationship between these concepts and if so, did they exist both before and after the course?

The first hypothesis, based on current literature, is that there will be a difference when contrasting the pre-course baseline measures with the post-course follow-up scores. The second hypothesis suggests that there will also be a relationship between adjustment to cancer, rumination, and fears of compassion both before, and after the course.

2.4 Part Two – qualitative methodology

This phase was designed to answer the following questions:

a) How do individuals who have experienced a meaningful and reliable shift in emotional affect after mindfulness, understand the change process?
b) How do they conceptualise and make meaning of the concepts of coping, rumination, and compassion in the light of their cancer and the mindfulness intervention?

2.5.1 Participants

A non-random, purposive sampling scheme was chosen to generate new insights about the phenomena and concepts under investigation (Miles & Huberman, 1994). The research question, with its emphasis on hearing the voices of the individuals, dictates that the qualitative is weighted more heavily than the quantitative (Morgan, 1998). Thus, a subset of participants who best provide the detail reflected in the quantitative results was chosen in a nested sample (Onwuegbuzie & Collins, 2007). This followed an examination of individual, clinically significant and meaningful change, as represented by the Reliable Change Index (RCI; Jacobson & Truax, 1991).

2.5.1.1 Inclusion criteria.

The inclusion criteria were the same for Part One. A pre-interview screening call assessed potential participants' suitability and whether they met the inclusion criteria, and this also allowed for a discussion about expectations. It was reiterated that individuals were not expected to be pressed on any subject matter generating significant distress (see ethics below) and that they could stop at any time.

2.5.1.2 Sample size.

Many issues affect the size of a qualitative sample with some suggesting “the guiding principle should be the concept of saturation” (Mason, 2010, para. 1) and this is frequently cited in health research as being a key to quality (Chamberlain, 2000). However, Braun and Clarke (2019) suggest a focus on quality over quantity and that “data saturation is not a particularly useful, or indeed theoretically coherent, concept” (p. 12).

The authors suggest a more nuanced approach is needed when determining sample size, including attention to the “scope and purpose of the project”, “the breadth and focus of the research question”, and “pragmatic constraints” (p. 11). Driven by these aspects and, pragmatically, by those who had consented, had reported change and were available, a sample size of ten was selected, which is considered sufficient to generate meaningful themes in a UK Professional Doctorate programme (Braun & Clarke, 2013).

2.5.1.3 Procedure.

The interviews concentrated on the sense-making behind any change and possible barriers in embracing it. This represents a more experiential understanding of complex and evolving phenomena, allowing space for multiple, even contradictory meanings, in participants’ accounts (Josselin & Willig, 2015).

The interview schedule (see Appendix 11) employed a funnelling approach, with questions targeting the following domains:

a) The self pre the mindfulness course
b) Reasons for joining and experiences of the group
c) Perceived changes and impacts on

    i. Coping styles
    ii. Ruminative thinking
    iii. Compassion in the context of cancer
    iv. Self-kindness

d) Barriers to the above and contextual factors influencing them.

Examples of questions include: how would you say you treated yourself before the mindfulness intervention? How would you describe any change afterwards in how you saw yourself? What did you notice or learn that was helpful? What was not? The focus of the interview was on any shifts in coping, ruminating thoughts and/or low mood, and any changes in perceived kindness, whether that be showing to others, accepting it, or showing it to the self.

While face-to-face interviews are most appropriate in sensitive research (Mathieson, 1999) such contact was not possible, due to the unforeseen coronavirus pandemic which struck just as participants' courses were ending. Online alternatives have been empirically tested within healthcare as a good secondary option (Deakin & Wakefield, 2013). While these methods have the advantage of improving access, it is important to acknowledge that online interviewing of any sort risks selective sampling and non-response bias from those unable to access the internet (Couper, 2011).

The University's Ethics Committee approved an amendment to the original consent form, regarding online interviewing (see Appendix 1b) and those participants who had consented to face-to-face interviews in the survey questionnaire (see Appendix 4), were sent a further consent to online interviewing (see Appendix 5).

Although 20 out of 22 participants had originally consented to interviews, some did not respond to follow-up emails with this new information. It is unclear why, however, in the circumstances of cancer symptom burden, cancelled treatments and a rampant virus, it was not felt ethical to pursue them.

2.6 Study analysis

2.6.1 Quantitative Analysis

2.6.1.1 Descriptive statistics and inferential statistics.

Baseline characteristics of the sample were measured using descriptive statistics. Parametric assumptions were then tested for normality using SPSS statistical software, with t-tests being used to evaluate change in pre- and post-outcome scores. The non-parametric Wilcoxon Signed Ranks Test was used to assess change when normality was violated, as it is a more sensitive, flexible statistical test for a non-normal data distribution and is also widely used in healthcare (Pett, 2015). A correlation analysis evaluated the association between mental adjustment to cancer, ruminative thinking, and fears of compassion.

2.6.1.2 Validity and reliability.

In this study, the Mental Adjustment to Cancer Scale (MACS) used Watson and Homewood’s (2008) revised two-factor, 33-item structure, with the summary ‘Positive Adjustment’ Scale representing attitudes and actions (previously the fighting spirit subscale) and the summary ‘Negative Adjustment’ Scale representing feelings (previously the helplessness/hopelessness, anxious preoccupation, avoidance, and fatalism subscales). Watson and Homewood suggest these are independent factors rather than being opposites, and that this higher order analysis has acceptable reliability and internal consistency, with Cronbach alpha scores for both, being .84. The authors suggest this revision provides a generalized, pragmatic, and overarching way of measuring adjustment to cancer, although like the original MAC scale, it does not distinguish traits or states, or identify problems with an individual's ability to cope with their disease and treatment.

The Ruminative Responses Scale (RRS), which measures reflection, brooding and depression-related thinking also has strong psychometric properties and reliability, with Cronbach alpha scores at or around .90 (Nolen-Hoeksema et al., 1994). A shorter, 10-item measure removing the depression subscale has been suggested for studies where items overlap with other measures of depressive symptomology (Treynor et al., 2003), however this 'reconsidered' scale has lower coefficient alpha and test-retest reliability, and as this study does not use a confounding measure examining depressive symptomology, the original 22-item was kept.

The Fears of Compassion Scale (FCS) measures the fear of compassion towards the self (how kind we are when we make mistakes or things go wrong), the fear of accepting compassion from others (whether we can experience kindness from others) and the fear of expressing compassion to others (representing the kindness we feel and show to others, based on a sensitivity to their thoughts and feelings) (Gilbert, 2010). Cronbach's alpha in Gilbert's original study shows acceptable reliability; with .85 for self, .87 from others and .78 for others.

The FCS was selected as the final scale in the questionnaire and as research suggests a sliding scale can maximise engagement and prevent drop-off (Funke et al., 2010), it was used for this part of the survey. Studies suggest participants using sliding scales can often choose the default, mid-point position (Bayer & Thomas, 2004), thus the Likert scale was changed to a six-point scale to counteract this tendency, increasing its reliability, validity and discriminating power (Preston & Colman, 2000).

2.6.1.3 Potential crises in representation and legitimation.

Some mindfulness studies in cancer care have reported methodological limitations which can cause crises of representation and legitimation, such as high course drop-out (Brotto & Heiman, 2007), small sample size (Chambers et al., 2011) and individuals not doing the homework provided (Kvillemo & Bränström, 2011). There is also disagreement on the minimum sample size for sequential explanatory mixed methods research with some recommending 30 participants for a correlational design (Creswell, 2002), and others more than double that (Onwuegbuzie & Collins, 2007). However, representation and legitimation in a small sample size can be strengthened by recognizing it as a multiple case sampling framework, where conclusions derived from the whole sample are applicable only to the sample itself, creating an internal statistical generalization, which increases confidence in the interpretation of the findings (Miles & Huberman, 1994; Tashakkori & Teddlie, 2010). The non-random (non-probability) sample represents an *analytic* generalizability, rather than a statistical one, with the setting and the individuals selected, because they are “information rich” (Patton, 1990, p. 169).

2.6.1.4 Ethics.

The study was ethically approved by City, University of London and follows suggested guidelines for both cancer research (Kennedy & Hulbert-Williams, 2015) and a best practice guide for mixed methods in healthcare for the Office of Behavioural and Social Sciences Research (OBSSR) (Creswell et al., 2011). Participants were made aware of anonymity and confidentiality in both phases before they signed the consent form (Appendices 4 & 5), as while this study protects their identity in the quantitative study, if participants wanted to engage in the second phase, they were required to leave a contact email. Safeguards were put in place to protect data by storing this information on an encrypted device. Those consenting and leaving personal information were informed of the possibility, but not the guarantee, of a follow up contact for Phase Two.

The OBSSR stresses that it is important not to over-burden participants who are experiencing difficulties in their health. While there is always a risk in cancer research of stirring up challenging emotions, this study focuses on the concepts of adjustment to cancer, rumination and compassion following mindfulness and the Part One questionnaire was designed to be short and limited to what was necessary to gain understanding of any shifts in the underlying processes.

The ethics of a control group were also considered. Control groups in pharmaceutical interventions are considered more straightforward than those used in ‘mind-body’ research in clinical populations (Kinser & Robins, 2013). An active control group, using an alternative condition, such as supportive group therapy, was not available, nor were there the resources to create them in six different centres at the same time as the MBI. A wait-list control would have been difficult to establish, as I could give no guarantee of a later intervention and a passive control group or no-treatment can be considered unethical in clinical populations (Kinser & Robins, 2013). There is sufficient evidence in the literature to demonstrate the efficacy of MBIs across a range of clinical groups; an RCT was not considered appropriate in this study where the focus is on the processes and mechanisms of inter- and intra-individual change and the mixed methods approach used to explore it.

2.6.2 Qualitative Analysis

2.6.2.1 Why Thematic Analysis?

Interviews were transcribed verbatim and analysed using Thematic Analysis (TA) which is most consistent with the study’s ontological and epistemological position, as it allows for a critical realist stance which acknowledges context. TA is not a methodology with theoretical assumptions, but a flexible method; an organic rather than a technical process (Terry et al., 2017) which seeks to identify, synthesize, and generate themes relating to the phenomena under investigation.

Reflexive Thematic Analysis was chosen over other forms of TA, such as coding reliability TA and codebook approaches, as it acknowledges the researcher's constructivist interpretation of the data (Braun & Clarke, 2019) without suggesting there is a single or 'correct' answer (Braun & Clarke, 2013). Other qualitative approaches were also considered and discounted. Interpretive phenomenological analysis (IPA) seeks patterns in data to understand phenomena, takes account of the uniqueness of an individual's experience and suggests researchers make their own thoughts explicit (Smith et al., 2009; Smith & Osborn, 2008). Although comfortable with IPA having used it before, the approach did not fit this research question which is interested in the participants' *understanding* of the elements, or processes, involved in any shifts in concepts, rather than individual *experiences* per se. IPA questions should be "open-ended and non-directive" (Willig, 2013 p. 87), whereas this study required a more focused inquiry. I also wondered whether I could effectively 'bracket' my assumptions and had doubts about whether my sample was homogenous enough.

Being constructivist, interpretive and flexible ruled out approaches such as Grounded Theory, which broadly suggests line-by-line coding for constant comparative analysis, along with data saturation (Charmaz, 2014). Discourse analysis was discounted too, as although it has similarities with TA in understanding patterns of meaning (Terry, 2016), this study is not *primarily* orientated towards the effects of language, nor in how it accedes, contests or challenges power. Qualitative Content Analysis was also ruled out, as its focus on content suggests searching for an implicit truth (Braun & Clarke, 2020). While all these approaches have merit, they would have made for a less iterative, organic study.

2.6.2.2. Ethics.

The Part Two semi-structured interviews raised more complex ethical issues than in Part One. The interview schedule paid attention to responsiveness, sensitivity and encouragement, while recognizing a need to check in with participants regularly, however, there is a risk in ‘active interviews’ of ‘prospecting’ for feelings (Holstein & Gubrium, 1995). Birch and Miller (2000) warn that researchers may deploy charm or rapport to encourage emotional disclosure if participants are unforthcoming, especially in an atmosphere of reciprocity and shared understanding, and participants may see the interview as a therapeutic opportunity, placing researchers into a role they are unable to fulfil. There is also a tension in my role as a researcher, as someone who’s both experienced cancer and who works therapeutically with those living with the disease (see reflexivity). It was important for both parties to be clear about what the interview *was* (information gathering for a study) and was *not* (therapy) and this was reiterated in the screening call.

Participants were also advised during the call that the interview would concentrate on the process of change, rather than in-depth questioning about the disease itself, however, participants were told that if difficult emotions arose during the interview, they could take a break, or stop at any time. Suggested support and resources were given in a debriefing letter at the end of the interview (see Appendix 12). The OBSSR guidelines say that mixed methods “may place a higher burden on participants than single-method approaches, but also may provide greater benefit” (Creswell et al., 2011, p. 28) and this study is aware of this tension throughout.

2.6.2.3 Analytic Procedure.

There are many different styles of TA, with the most cited being from Braun and Clarke’s 2006 paper, which follows a six-stage process:

1. *Data Familiarisation* **-** transcription/reflective reading
2. *Initial coding* **-** identifying important features of the data relevant to the question

3. *Generating initial (potential) themes* - identifying broader patterns of meaning
4. *Reviewing* – checking and refining candidate themes against the data
5. *Defining and naming themes* – working out the ‘story’, scope and focus for themes
6. *Writing up* - weaving together the analytic narrative and data

These phases are sequential however the analysis is recursive, going back and forth between stages to guide the analysis, rather than being a set of tools or rules. Braun and Clarke have redefined their TA approach as ‘Reflexive Thematic Analysis’, acknowledging the researcher’s role at the heart of the process with themes actively created and interpreted, rather than being ‘found’ or passively emerging from the data (Braun & Clarke, 2013, 2019, 2020).

Reflexive TA does not describe individual experiences but examines “factors relating to key elements of the experience” (Braun & Clarke, 2013, p. 181), enabling common themes to be developed while paying attention to sociocultural contexts and ‘actionable outcomes’ (Braun & Clarke, 2020). Reflexive TA identifies *what* is being assumed, then interrogates whether it holds, by using a deliberate, knowing, and transparent approach, which seems appropriate for this mixed methods research. It also uses the researcher as storyteller, actively interpreting and (re)engaging with the data in a reflective and reflexive way.

2.6.2.4 Quality markers and ‘validity’.

Validity, reliability, and generalizability are considered appropriate terms for quantitative research; but there is considerable debate about their usefulness for evaluating qualitative research (Sandelowski, 1993). Lincoln and Guba (1985) suggest ‘truth value’ rather than ‘validity’, as it recognizes different perspectives and the possibility of researcher bias (p. 290). They suggest ‘reliability’ can be replaced by ‘consistency and neutrality’, which represents a level of trustworthiness and transparency by making a researcher’s epistemological position and experiences clear. ‘Applicability’, the authors suggest, can be used instead of ‘generalizability’, in other words, an awareness of whether findings can be applied in other contexts and settings.

Yardley (2007) built on these criteria in relation to health studies, urging researchers to consider the impact and importance of their study in suggesting changes to the way we consider attitudes to illness and health, by exploring the concepts that drive a more positive approach, in this case, how mindfulness can help shift ruminative thinking, negative coping and fears of compassion in those with cancer. While both sets of criteria have been adhered to in the qualitative part of this research, this is a mixed methods study, which again, has its own quality markers to ensure mixed methods do not become ‘data soup’ (Tashakkori & Teddlie, 1998).

2.6.2.5 Quality markers in mixed methods.

Teddlie and Tashakkori suggest abandoning the term *validity* in mixed methods altogether, claiming its meaning is so diverse and overused as to be meaningless. They suggest *inference quality* best represents the internal validity, trustworthiness and credibility needed for a mixed approach (Teddlie & Tashakkori, 2003). Taking a critical realist perspective, this is upheld if claims about meanings and changes in processes are supported by the data, while alternative explanations are also fully explored (Maxwell & Mittapalli as cited in Tashakkori & Teddlie, 2010). While different quality criteria are used for quantitative and qualitative analysis, this study also adheres to O’Cathain’s mixed methods criteria which suggest:

- A *foundational element* - situating the research according to a comprehensive review of literature,

- A *rationale transparency* - where the justification of mixed methods is transparent,
- A *planning transparency* - where the paradigm, design, data collection, and analysis and reporting are clearly set out and
- *Study feasibility* - where issues such as timing and expertise are made clear (O'Cathlain as cited in Tashakkori & Teddlie, 2010).

The foundational element of this research is driven by gaps in the literature, the rationale for mixed methods is its value in understanding changes that underpin change and process while attending to the richness and diversity of individual experience, and the design for collecting, analysing, and reporting the data has been outlined above. Study feasibility relied on participants completing post-questionnaires soon after the course had finished, to minimise recall bias, and on my expertise in analysing the outcome statistics to determine selection for Part Two, to arrange interviews before too much time had elapsed.

2.7. Reflexivity

Being reflexive throughout the study is "the key to validity" (Finlay, 2002) and requires a "thoughtful, conscious self-awareness" (p. 532), which is dynamic, subjective, immediate, and continuing. It acknowledges that a researcher's behaviour can affect participants' responses and influence research findings; reflexive analysis examines the impact of me on them, and them on me. This "bending back upon oneself" (Finlay & Gough, 2003, p. ix) can be demanding. The reason for choosing the research question was my personal experience and a commitment to affect change, yet when deliberating whether to academically invest in this area, or into another, less emotive one, the latter seemed safer, more contained. I agree with the sentiment that research which "doesn't break your heart, just isn't worth doing anymore" (Finlay, 2009 p. 15), however, I also acknowledge the tensions in this 'insider-outsider' role in healthcare research (Dwyer & Buckle, 2009; Råheim et al., 2016). This study is not conducted from the position of a Maggie’s ‘insider’, as it would have compromised the research, and the need for independence, flexibility and freedom was also stressed to the Centre’s Clinical Lead. My experience as a cancer-care therapist and my own history gave me an understanding of the emotional impact of cancer, however, personal disclosure risked bias and excessive self-analysis, which is against the aims of the research (Finlay, 2002).

A balance had to be struck, on the one hand acknowledging why the research question had been chosen, the factors influencing it and its potential impact on me; on the other, the need to fully hear the voice of the participants, one of the motivating reasons behind the research. There was a tension in how transparent to be, which I also felt in my cancer counselling. While I wanted individuals to sense the importance of the issue to me, I felt disclosing my experience might confound results, just in the same way as it might affect therapy.

I discussed this in supervision, kept a reflexive diary and saw a personal therapist, however immersion in this environment was challenging. I developed strategies for coping with the emotional impact, such as using pacing and breaks (Gilbert, 2001, p. 11). As Malacrida (2007) writes, true reflexive research “should involve emotional care, not only for participants, but for researchers themselves” (p. 1339). However, there are tensions; at one stage I was interviewing a participant about breast cancer having just come out of surgery myself and these ethical considerations are discussed in more detail later.

Chapter Three: Analyses

3.1 Introduction

The data for Parts I and Part II was gathered sequentially, to examine outcomes, processes, and experiences (Plano Clark & Badiee, 2010) using both sets of data to compare, validate, and triangulate results, to enrich and enhance participants' meaning making. The quantitative analysis included paired samples t-tests to compare pre- and post-intervention differences, and correlations to explore relationships between coping, rumination, and fears of compassion. The Reliable Change Index (RCI) was used to identify a selection of individuals who reported significant shifts and their transcribed interviews were analysed using Reflexive Thematic Analysis (Braun & Clarke, 2020).

3.1.1 Response rate for Parts I and 2

Of the 23 Maggie's centres contacted between October and December 2019, seven were running eight-week mindfulness interventions between January and April 2020 and gave consent to distribute leaflets, posters, and cards with Quick Response (QR) codes, linking to the questionnaires. Three centres had 12 course attendees each, three had eight and one had seven, meaning 69 potential participants across the seven centres. Of those, 40 people consented and returned the pre-course (T1) questionnaire in January 2020, representing an initial response rate of 58%. Some answers were incomplete, and these responses were counted as missing data and excluded, leaving a pre-course (T1) sample of 31 participants, representing a response rate of 45%. This is similar to other web-based surveys of cancer survivors (43%) (Millar et al., 2019).

Towards the end of the mindfulness-based intervention, personalised reminders with a QR code were sent to the mindfulness teachers, the head of centres and the participants who had consented to be contacted, to help augment response rates for the post-course (T2) questionnaire (Menon & Muraleedharan, 2020). Of the original 31 participants, nine failed to complete the course. Three were on a course cancelled due to coronavirus, three dropped out after ill health and the remaining three for undisclosed reasons. 22 individuals across six centres finished both the eight-week mindfulness course and successfully completed the pre- and post-course questionnaires with no missing data. Of the 22 participants who successfully completed the course and both questionnaires, 20 consented to a follow-up interview, suggesting a response rate of 91%.

3.1.2. Power

A post hoc power analysis revealed that on the basis of the mean, between-groups comparison effect size observed in the present study (see analyses for Cohen's *d* effect sizes respectively), an *N* of approximately 46 would be needed to obtain statistical power at the recommended .80 level for moderate effect sizes (Cohen, 1988). However, smaller sample sizes are sufficient in mixed-methods feasibility studies, and sample size justification is often considered more important than a formal calculation (Julious, 2005; Sim & Lewis, 2012). Based on the justification in 2.4.2.1, a sample size of *N* 22 was deemed appropriate for Part One of this study.

3.2 Quantitative Results

3.2.1. Parametric assumptions

SPSS v25 statistical software was used to test for normality of distribution and multicollinearity. The assumption of normality was satisfied for all subscales of the Mental Adjustment to Cancer Scale (MACS) and the Ruminative Responses Scale (RRS) at pre- (T1) and post- (T2) questionnaire. Skew and kurtosis did not exceed 0.8 or 2 respectively. Shapiro Wilks tests, generally used for samples of less than 50, and Kolmogov-Smirnov tests, which measure the goodness of fit, indicated that the scores were normally distributed (p = >0.05). A probability-probability (P-P) plot also showed normal distribution across both the MACS and RRS. There were two outliers in the negative adjustment to cancer subscale in T1, but they did not change the regression line. There were no outliers on this scale at T2.

The assumption of normality was violated for the Fears of Compassion scale (FCS) in both T1 and T2. Shapiro Wilks tests were statistically significant across all subscales (*p* = <0.05) as were the fear of compassion from others and for self in the Kolmogov-Smirnov tests (*p* = <0.05). Skewness and kurtosis for the subscale relating to fear of compassion for the self were above 0.8 and 2 respectively. One case was an outlier in both T1 and T2 and although there was no significant association, it is worth noting that this participant reported scores significantly higher than the mean (+3 *SD*).

3.2.2. Analysis for pre-post change in measures

The changes in scores between T1 and T2 in the Mental Adjustment to Cancer Scale (MACS) and the Ruminative Responses Scale (RRS) were analysed using a two-tailed, paired samples t-test. A two-tailed Wilcoxon Signed Ranks Test was used to analyse changes in the Fears of Compassion scale (FCS). Pearson correlations were run to examine relationships between participants' adjustment to cancer, rumination, and fears of compassion, both before and after the course. All scales and subscales appeared to have good internal consistency in both T1 and T2, with a range of between $\alpha = .75$ and .95.

3.2.3. Sociodemographic and Clinical Characteristics

There were 20 women and two men in this study. All participants were over 45 and 64% (*n* = 14) had University or post-graduate qualifications. Half worked full-time, part-time or were self-employed (*n* = 11), 36% were retired (*n* = 8) and 9% (*n* = 2) were unemployed or too ill to work. Most, 68% (*n* = 15), identified as white British, with 86% (*n* = 19) specifying English as their main language. The majority were living with or beyond breast cancer, with other cancers including uterine/endometrial, ovarian, prostate, bowel, and kidney cancer. The stages ranged from stage 0 where the cancer is small and contained to stage 4, where it has spread from its origin to another organ. Some participants were in active treatment, others were in remission. Cancer type, stage and medical treatment are listed in Table B1. Comparisons of available demographic data of those with cancer in a study evaluating the effectiveness of mindfulness on well-being in a similar community setting, suggest the sample was comparable (Hoffman et al., 2012a). All sociodemographic details are listed in Appendix 13.

Table B1

Participants' Cancer, Stage and Treatment

Characteristic	Number *(n)*	Percentage *(%)*
Cancer diagnosis		
Less than 12 months	8	36
13-24 months	7	32
2-5 years	2	9
More than 5 years	5	23
Stage of cancer		
Stage 0	1	4.5
Stage 1	6	27
Stage 2	4	18
Stage 3	6	27
Stage 4	3	13
Missing	2	9
Type of cancer		
Breast	14	64
Blood	2	9
Uterine/endometrial	2	9
Bowel	1	4.5
Kidney	1	4.5
Ovarian	1	4.5

Characteristic	Number *(n)*	Percentage *(%)*
Prostate	1	4.5
Treatment		
Surgery	18	82
Radiotherapy	13	59
Treatment		
Chemotherapy	14	64
Hormonal	10	45.5
Letrozole	2	9
Leuprorelin acetate	1	4.5
Tamoxifen	4	18
Biological	6	27
Trastuzumab	2	9

3.2.4 Main outcomes in T1 vs T2

3.2.4.1 Mental adjustment to cancer and rumination.

A paired samples t-test compared participants' adjustment to cancer and rumination scores before and after the mindfulness-based intervention, with 0.10, 0.30 and 0.50 considered small, medium, and large effect sizes. There were statistically significant differences in the pre (T1) and post (T2) scores for negative adjustment to cancer, and depressive and brooding rumination, although not reflective rumination.

Negative reactions to cancer on the MACS were significantly lower after the mindfulness course (M = 31.00, SD = 6.71) than before it (M = 36.18, SD = 7.24); t (21) = 4.68, p <.001 and the effect size was large (d = 0.5). Depressive rumination scores on the RRS were significantly lower after the mindfulness intervention (M = 22.05, SD = 7.43) than before it (M = 25.82, SD = 7.50); t (21) = 2.59, p < .05 with a medium effect size (d = 0.3). Participants also showed lower levels of brooding rumination after the course (M = 9.18, SD = 2.95) than before it (M = 10.59, SD = 3.27); t (21) = 2.58, p <.05 with a medium effect size (d = 0.3). There was no significant difference in the reflective rumination mean and *p* value (see Table B2 and Figure B1).

Table B2

Paired Sample t-tests in Participants (N = 22) Adjustment to Cancer and Rumination

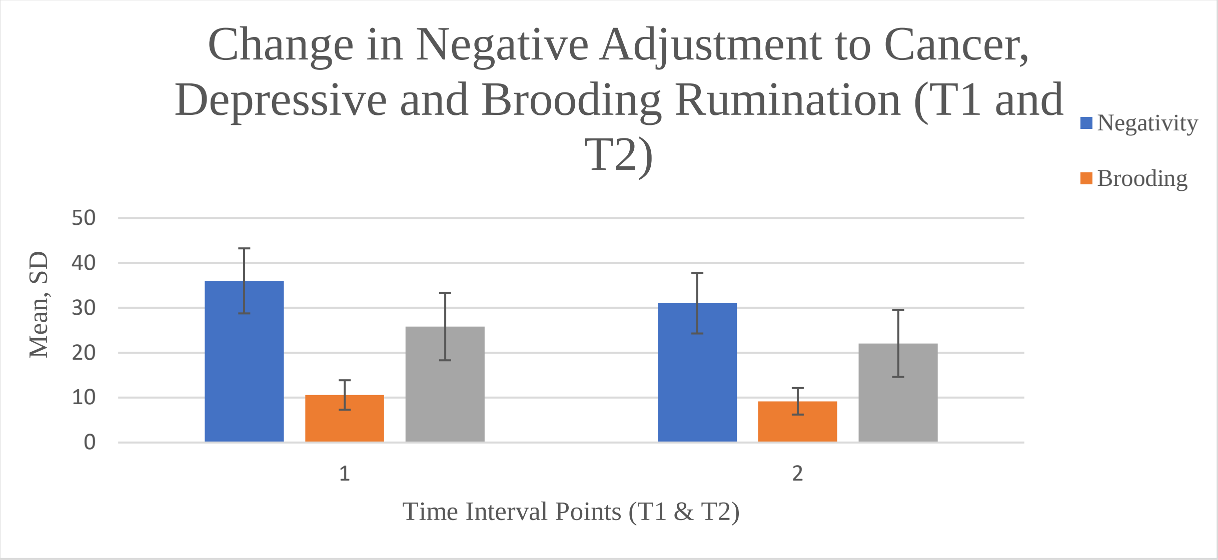
	M (SD) T1	***M (SD) T2***	***MD***	***t***	***p***
MACS					
Negative adjustment to cancer	36.18 (7.24)	31.00 (6.71)	5.18	4.68	<.001**
Positive adjustment to cancer	48.36 (5.59)	50.18 (6.14)	2.95	-1.75	.094
RRS					
Depressive rumination	25.82 (7.50)	22.05 (7.43)	3.77	2.59	.017*
Brooding rumination	10.59 (3.27)	9.18 (2.95)	1.40	2.58	.017*
Reflective rumination	10.05 (3.13)	9.55 (3.23)	.50	-.81	.426

Notes: **p* = <.05. ** *p* = <.01

Abbreviations: MACS, Mental Adjustment to Cancer Scale. RRS, Ruminative Responses Scale. T1 = pre-outcome (week 0), T2 = post-outcome (week 8). *M* = mean, *SD* = standard deviation, *MD* = mean difference, *t* = test score, *p* = sig.

Figure B1

Changes in Negative Adjustment to Cancer, Depressive and Brooding Rumination (T1 and T2)



3.2.4.2 Fears of compassion.

Results of the Wilcoxon signed rank test on the Fears of Compassion Scale (FCS) and subscales revealed a statistically significant difference in fears of expressing kindness and compassion towards the self, which decreased between T1 (*M* = 16.50, *SD* = 15.13) and T2 (*M* = 13.18, *SD* = 16.75), with a medium effect size (*Z* = -2.019, *p* <.05, *d* = 0.4). This was not the case with fears of responding to the expression of compassion from others (*Z* = -1.31, *p* >.05, *d* = 0.2) or fears of expressing compassion for others (*Z* = -1.04, *p* >.05, *d*= 0.2) (see Table B3).

Table B3

Wilcoxon Signed-Rank Tests in Participants (N = 22) Regarding Fears of Expressing Compassion for Others, from Others and for Self in T1 and T2

	M (SD) T1	***M (SD) T2***	***MD***	***Z***	***p***
FOCS					
Fear of compassion for others	15.32 (12.39)	14.18 (13.15)	1.14	-1.04	.29
Fear of compassion from others	15.05 (15.23)	12.64 (13.73)	0.5	-1.31	.14
Fear of compassion for self	16.50 (15.13)	13.18 (16.75)	3.21	-2.02	.043*

Notes: **p* = <.05. ** *p* = <.01

Abbreviations: FOCS = Fears of Compassion Scale. T1 = pre-outcome (week 0), T2 = post-outcome (week 8). *M* = mean, *SD* = standard deviation, *MD* = mean difference, *Z* = test score, *p* = significance.

3.2.5 Secondary outcomes

Pearson's correlation coefficients were calculated to assess the size and direction of the relationships between coping, rumination, and fears of compassion.

3.2.5.1 Mental adjustment to cancer and rumination.

Results of the Pearson correlations indicated that there was a significant positive association between negative adjustment to cancer and depressive rumination before the mindfulness-based intervention, *r* (20) = .64, *p* = .001 and after it, *r* (20) = .53, *p* = .010. There was also a moderate positive correlation with brooding rumination before, *r* (20) = .45, *p* = .035 but not after the course, and negative adjustment was negatively associated with a positive adjustment to cancer in both T1, *r* (20) = -.45, *p* = .036 and T2, *r* (20) = -.44, *p* = .037.

Depressive rumination was strongly positively correlated with brooding rumination both before the intervention, *r* (20) = .76, *p* <.001 and after it, *r* (20) = .80, *p* <.001. Brooding rumination was also moderately positively correlated with reflection in T1, *r* (20) = .43, *p* = .044, with a stronger positive association in T2, *r* (20) = .51, *p* = 0.14. We also found a highly significant, positive association between reflection and depressive rumination, *r* (20) = .75, *p* <.001, fears of compassion for others, *r* (20) = .61, *p* = .002, from others, *r* (20) = .62, *p* <.001 and towards the self, *r* (20) = .69, *p* <.001 *after* the course, but not before it .

3.2.5.2 Fears of compassion.

Both before and after the intervention, the fear of expressing self-compassion was strongly positively correlated with fear of responding to the expression of compassion *from* others, *r* (20) = .81, *p* <.001 and showing it *to* them, *r* (20) = .82, *p* <.001. In T1, there was also a strong positive correlation between fears of self-compassion and depressive, *r* (20) = .60, *p* <.001 and brooding rumination, *r* (20) = .49, *p* =.019 which was also shown in T2, *r* (20) = .70, *p* <.001 and *r* (20) = .69, *p* =.001 respectively (see Tables B4 and B5).

Table B4

Pearson's Correlations in Participants (N = 22) in T1 (Week 0, Pre-Intervention)

	Negative	Positive	Depression	Brooding	Reflection	FoC for	FoC from	FoC self
Negative	.							
Positive	-.45*	.						
Depression	.64**	-.17	.					
Brooding	.45*	-.12	.76**	.				
Reflection	.15	.31	.16	.43*	.			
FoC for	.28	.06	.53*	.59*	.39	.		
FoC from	.55*	-.21	.59**	.51*	.28	.83**	.	
FoC self	.50*	-.19	.60**	.49*	.30	.81**	.83**	.

Notes: * *p* = <.05 (two-tailed) ** *p* = <.01 (two-tailed)

Abbreviations: Negative = negative adjustment to cancer. Positive = positive adjustment to cancer. Depression = depressive rumination. Brooding = brooding rumination. FoC for = fear of compassion for others. FoC from = fear of compassion from others. FoC self = fear of compassion for self

Table B5

Pearson's Correlations in Participants (N = 22) in T2 (Week 8, Post-Intervention)

	Negative	Positive	Depression	Brooding	Reflection	FoC for	FoC from	FoC self
Negative	.							
Positive	-.45*	.						
Depression	.53*	-.20	.					
Brooding	.35	-.21	.80**	.				
Reflection	.39	.14	.75**	.51*	.			
FoC for	.23	.13	.76**	.71**	.61**	.		
FoC from	.39	-.11	.83**	.71**	.62**	.90**	.	
FoC self	.16	.18	.70**	.65**	.69**	.81**	.82**	.

Notes: * *p* = <.05 (two-tailed) ** *p* = <.01 (two-tailed) Abbreviations: Negative = negative adjustment to cancer. Positive = positive adjustment to cancer. Depression = depressive rumination. Brooding = brooding rumination. FoC for = fear of compassion for others. FoC from = fear of compassion from others. FoC self = fear of compassion for self

3.2.5.3 Self-criticism.

Some ‘brooding’ questions in the Rumination Responses Scale (RRS) relate to a self-critical approach (why can’t I handle things better? why do I always react this way?), as do some statements in the Fears of Compassion (FCS) subscale for self (I find it easier to be critical towards myself rather than compassionate; I fear that if I become kinder and less self-critical to myself then my standards will drop, I fear that if I become too compassionate to myself I will lose my self-criticism and my flaws will show).

When these self-critical questions were summed, there was a statistically significant change between T1 and T2 (*MD* = 1.81, *SD* = 2.55); *t* (21) = 3.33, *p* < .005, with most participants (*n* = 18) reporting a decrease in self-criticism between T1 (*M* = 9.82) and T2 (*M* = 8.00). This self-criticism subscale appeared to have good internal consistency, *α* = .86. Before and after the course, self-criticism was strongly positively correlated with fears of expressing compassion for others (*p* < .001) and fears of responding to the expression of compassion from others (*p* < .001).

3.2.6 Intra-individual changes between T1 and T2

The changes in repeated measures in Part One analyses general shifts in perceived thinking and behaviour in the participants as a group, between T1 and T2. Part Two of this study concentrates on the individual case in context. For change to be considered clinically significant and for meaningful gains as well as deteriorations to be noted in a participant, it must also be determined as being statistically reliable (Britton, 2019).

The Reliable Change Index (RCI; Jacobson & Truax, 1991) computes the standard error of measurement and the standard difference score for every individual to calculate whether there is reliable change that is not likely due to an error of measurement alone. It uses the test-retest, or reliability of each scale and the standard deviation of the reference, or baseline (T1) measurement, to compute an individual's standardized score. The RCI determines whether the difference in scores is in =/-5% area of error distribution and can be used to select participants for further research (Zahra & Hedge, 2010). In this sample, most participants (*n* =18) reported reliable change (RC) in at least one measure between T1 and T2, such as significant decreases in negative adjustment to cancer, brooding and depressive rumination and fear of compassion for others, from others and towards the self. Several participants (*n* = 5) also reported increases in RC (see Tables B6 & B7).

Of the participants who reported a statistically significant change and who consented to be involved in Part Two, 10 were selected for interview. Their names (pseudonyms), cancer type and stage, current medical condition and reliable change scores are in Table B8, and a fuller description of their characteristics are in the qualitative analysis.

Table B6

Reliable Change Index (RCI). Raw participant scores (N = 22) between T1 (pre-intervention) and T2 (post-intervention)

Case *Qual	Negative adjustment	Positive Adjustment	Depressive Rumination	Brooding Rumination	Reflective rumination	FoC for Others	FoC from Others	FoC for self	Cancer	Stage	Time since diagnosis
1	45/34	43/45	25/22	11/9	8/9	5/15	18/25	4/8	Kidney	-	>1 yr.
2	34/30	51/55	23/24	9/11	8/7	27/27	18/23	18/5	Breast	1	1-2 yrs.
3	50/43	45/41	38/36	16/15	13/13	22/24	33/31	33/25	Breast	1	1-2 yrs.
4 *	34/27	45/44	21/16	8/7	8/8	12/1	7/1	4/1	Breast	2	>1 yr.
5 *	37/43	44/49	26/29	7/10	13/14	10/12	16/13	31/16	Uterine	2	>1 yr.
6 *	34/22	49/57	21/16	10/5	13/10	20/4	23/0	14/2	Breast	0	< 5 yrs.
7	30/27	55/56	26/22	14/12	18/11	30/29	12/10	16/16	Uterine	1	1-2 yrs.
8	46/36	41/42	33/35	14/15	11/16	40/38	47/45	58/52	Breast	2	>1 yr.
9	40/30	52/50	38/32	15/14	9/10	37/34	25/28	39/26	Blood	4	< 5 yrs.
10 *	36/28	53/65	34/31	15/12	13/15	38/39	45/35	38/65	Breast	3	< 5 yrs.
11	43/35	48/50	29/12	8/5	10/5	1/0	2/2	9/2	Blood	1	> 1 yr.
12 *	34/23	47/48	35/17	13/9	10/5	6/3	5/1	7/1	Breast	3	1-2 yrs.
13	18/23	54/48	14/12	6/7	6/6	5/2	0/0	0/0	Breast	4	< 5 yrs.
14	23/20	58/58	17/21	8/7	8/10	5/5	0/3	5/11	Breast	1	> 1 yr.
15 *	38/34	49/47	30/17	16/9	8/6	6/0	0/0	7/4	Breast	3	< 5 yrs.
16 *	31/28	56/52	19/19	12/8	15/11	8/0	3/0	4/1	Bowel	4	2-5 yrs.
17 *	35/32	44/45	30/18	9/10	5/5	4/2	1/0	11/5	Breast	2	1-2 yrs.
18	39/26	54/54	20/14	8/6	9/7	8/18	13/17	14/21	Ovarian	3	1-2 yrs.
19 *	36/38	42/45	18/29	8/9	9/11	13/11	16/12	26/10	Prostate	-	2-5 yrs.
20	41/40	53/58	21/18	9/7	12/12	9/11	4/5	6/2	Breast	1	>1 yr.
21 *	41/37	44/44	35/29	11/7	8/10	25/26	39/24	19/12	Breast	3	1-2 yrs.
22	31/26	37/51	15/16	6/8	7/9	2/11	0/3	0/5	Breast	3	1-2 yrs.

Key: RC (reliable change) yellow = significant decrease between times (*p* <0.05), green = significant increase between times (*p* <0.05),
Abbreviations: FoC = Fears of Compassion, *qual = qualitative participants, yr. = year, - = information not provided

Table B7

Reliable Change Index (RCI). Participant scores showing reliable increase/decrease between T1 and T2

Participant (pseudonym)	Negative Adjustment	Positive Adjustment	Depressive Rumination	Brooding Rumination	Reflective Rumination	FoC for others	FoC from others	FoC for self
1	-3.10							
2								-2.29
3								
4* (Jan)						-2.06		
5* (Anna)								-2.65
6* (Lucy)	-3.38			-2.48		-3.01	-4.77	-2.12
7					-3.16			
8	-2.81				2.25			
9	-2.81		-2.00					-2.29
10* (Barbara)		3.31					-2.07	4.76
11			-5.66		-2.25			
12* (Maya)	-3.10		-6.00		-2.25			
13								
14								
15* (Sam)			-4.33	-5.45				
16* (Sally)				-1.98				
17* (Tanya)			-4.00					
18	-3.66		-2.00					
19* (Henry)			3.66					-2.82
20								
21* (Emma)			-2.00	-1.98		-2.82		
22		3.86						

RCI is calculated by dividing the difference between the pre-treatment/post-treatment scores by the SE of the difference. If the RCI is **more than 1.96**, (95% C.I) the difference is reliable, i.e., a change of that magnitude would not be expected due to chance or the unreliability of the measure. If the RCI score is less than 1.96, there is not considered to be reliable change and the score is not reported. RCI = (post-test - pre-test) / $SE_{meas.}$

Table B8

Qualitative Participants with Cancer Type, Stage, Treatment, Current Condition and Reliable Change Between T1 and T2

	Jan	Anna	Lucy	Barbara	Maya	Sam	Sally	Tanya	Henry	Emma
Cancer										
Type and stage	Breast 2	Uterine 2	Breast 0	Breast 3	Breast 3	Breast 3	Breast 2	Bowel 4	Prostate	Breast 3
Treatment										
Surgery	yes	yes	Yes	yes	yes		yes	yes	yes	yes
Radiotherapy	yes	yes	Yes	yes			yes		yes	yes
Chemotherapy				yes	yes	yes	yes	yes	yes	
Hormonal	yes		Yes				yes		yes	yes
Biological										
Current condition	Recent Surgery	Watch & wait	Cleared	Remission	Remission BRCA	Incurable	Recovering	Incurable (palliative)	Incurable	Remission
RCI T1/T2 scores										
Negative adjust.			-3.38		-3.10					
Positive adjust.				3.31						
Depressive rumin					-6.00	-4.33		-4.00	3.66	-2.00
Brooding rumin.			-2.48			-5.45	-1.98			-1.98
Reflective rumin.					-2.25					
FoC for others	-2.06		-3.01							
FoC from others			-4.77	-2.07						-2.82
FoC for self		-2.65	-2.12	4.76					-2.82	

Abbreviations: adjust. = adjustment, rumin. = rumination, FoC = fear of compassion, RCI = reliable change index

3.3 Qualitative Results

3.3.1 Descriptive information of participants

Pseudonyms are used and all geographical or other identifying information has been removed. For clinically significant changes to individuals' pre- and post-intervention scores as measured by the Reliable Change Index, and their cancer status and treatment, please refer to Table B8. These are also summarised below.

Jan

Jan is in her late 40s and is married with a son who lives at home. She was diagnosed with stage 2 breast cancer in April 2019 and underwent surgery, followed by radiotherapy and hormonal treatment. The active treatment finished a few months before she began the mindfulness course. The surgery has restricted movement in her arm, which affects her profession, and she is signed off work. Jan's scores indicate a meaningfully positive shift in her fears of expressing compassion for others after the mindfulness intervention.

Anna

Anna is in her mid-50s and is married with one child. She began the course with stage 1 uterine cancer. Stage 1 means that the cancer is small, however it is classed as grade 3, which means it may spread aggressively. By the end of the course, the cancer had been reclassified as stage 2. She is currently on a 'watch and wait' treatment basis with a 30% chance of recurrence. She began the mindfulness course a year after surgery and radiotherapy. Her scores suggest a drop in her fears of expressing kindness to herself.

Lucy

Lucy is in her mid-60s, single and lives alone. She has retired from working as the director of a small company. In 2015, she had stage 0 breast cancer and had surgery and hormone treatment. She is now clear from cancer and lives with non-cancer related back pain. After the mindfulness course, Lucy's scores suggest a decline in her negative reactions to her cancer, a fall in her brooding ruminative thinking, and clinically significant decreases in her fears of expressing compassion to others, accepting it from them and showing it towards herself.

Barbara

Barbara is in her 60s, married with adult children, and has retired from her office job. She had stage 3 breast cancer in 2014 and her treatment, which included surgery, radiotherapy, and chemotherapy finished a year later. Although in remission, she experiences severe side effects from the treatment which causes fatigue and limits her ability to be active. Barbara's scores suggest an increase in her positive adjustment to cancer and a decline in her fears of responding to the kindness of others. Her fears of showing kindness to herself increased significantly after the intervention.

Maya

Maya is in her mid-50s and is married with three children. She had stage 3 breast cancer and has the inherited BRCA (breast cancer) gene. She had surgery and chemotherapy, which finished less than a year before the mindfulness course began. She reports experiencing nerve damage from surgery and describes being in chronic and constant pain. Maya's scores suggest a decline in her negative reactions to cancer and her depressive and reflective rumination following the course.

Sam

Sam is in her early 60s, retired with children and grandchildren, and lives at home with her husband. She is living with stage 3 breast cancer, with secondaries in her bones and liver. She is receiving chemotherapy and her cancer is incurable. According to her results, Sam reported a statistically significant decrease in both her depressive and brooding rumination after the mindfulness intervention.

Sally

Sally is in her early 50s, married and retired. She has stage 2 breast cancer and has had surgery, radiotherapy, chemotherapy and was on hormone tablets and biological therapy which stopped a year before the mindfulness intervention began. Sally’s scores suggest a meaningfully significant decrease in her brooding rumination after the course.

Tanya

Tanya is almost 60 and married with two adult children. She has stage 4 metastatic bowel cancer, with secondaries in her liver. She’s on chemotherapy and had her third operation three weeks before the mindfulness course started. Her cancer is incurable. Tanya’s scores suggest a meaningfully significant decline in her depressive rumination after the course.

Henry

Henry is in his late 60s, married and retired and was diagnosed with prostate cancer in 2017. He had surgery and radiotherapy, and his cancer returned two years later. He is on hormone therapy and his cancer is incurable. Henry’s scores suggest his depressive rumination went up after the course and his fears of expressing compassion towards himself, went down.

Emma

Emma is in her late 40s, is self-employed and lives with her husband and children. She was diagnosed with stage 3 breast cancer in 2019 and had surgery and radiotherapy. She is still on hormone therapy. Emma had the ‘all clear’ just after the mindfulness course finished and is on a three-month review, and currently having tests following a query of cervical cancer. Her scores suggest a drop in depressive and brooding rumination, and a decline in her fears of expressing compassion to others.

3.3.2 Analysis of Transcripts

The mean interview time was 62.5 minutes, and the 10 interviews were transcribed and analysed according to Braun & Clarke’s recursive, reflexive six-stage approach of data familiarization, coding, theme development, revision, naming, and writing up. This was then measured against their 15-point checklist of criteria for good Thematic Analysis (Braun & Clarke, 2006) (Appendix 14).

The advantage of thematic analysis (TA) is its flexibility, where themes can be identified in a ‘bottom-up’ way, based on what develops from the data, or a ‘top-down’ approach, using the data to explore ideas and theories, with some studies, such as this one, combining both (Braun & Clarke, 2013). The participants for Part Two had been chosen based on a clinical and meaningful change in their intra-individual scores as measured by the Reliable Change Index (RCI), thus a perceived shift had already been established. The analysis for this part of the study was based on a critical, constructivist approach which identified concepts and ideas that underpinned the explicit content, to explore it for assumptions and meanings. This meant combining both top-down and bottom-up approaches, to see the surface-level, descriptive content while also using an interpretive lens to look beneath. Braun et al., (2016) suggest most thematic analyses include this approach of combining both semantic and latent, and inductive and deductive elements.

Codes identified what was of interest in the dataset in relation to the original study question, and these ‘building blocks’ were combined to establish themes, or meaningful patterns in the data. Braun and Clarke (2013) consider two to six themes as being appropriate for an analysis chapter in a doctoral thesis, with each theme having a central organising concept, capturing its essence, and with subthemes beneath, which share the same concept, but focus on a specific element. This TA approach does not rely on a coding reliability framework, established by researchers such as Boyatzis (2009), but is a more organic, immersive, active, and reflexive way of analysing data (Braun & Clarke, 2006, 2013). Although a hypothesis had been established and confirmed (that of change), the analysis did not go searching for evidence to back up preconceived themes, as if they existed already. Rather, it was a more flexible, iterative approach, where my active engagement with the codes created the analytic output. This organic exploration of the transcripts meant being open to the possibility of both confirmation and contradictions with the quantitative data.

3.3.2.1 Phases 1-2: Familiarization and coding.

The process of immersion in the data to become intimately familiar with its content took more than a month and involved a thorough engagement with the transcripts, reading and re-reading the data and making notes about what I felt might be interesting and relevant to the research question. Although there was some analysis at this point, the data was initially approached in a more informal, curious way, asking questions about how participants were making sense of their shift in thinking and whether their accounts might be similar or different to each other. Coding involved labelling segments of data, trying to evoke them, and this often meant tweaking codes, collapsing them, expanding them, and keeping them open to return to for a second, or third reading. Some codes were semantic, capturing content (‘the fear of recurrence’) while others were latent (‘the role of the self-critic’) and by the end of four weeks, around 40 codes were identified across the dataset (see Appendix 15)

3.3.2.2 Phases 3-5: Theme development, refinement, and naming.

The codes and coded data were organized into candidate themes and reviewed and revised, continually referencing back to the research question. However, these initial candidate themes tended to be descriptive, and it took a further month to make the creative and ‘interpretative leap’ to capture the essence of the findings, while also highlighting the emotive, purposeful aspect of the theme, to create a more nuanced and compelling understanding of the overall ‘story’. This meant going back to the idea of the central organizing concepts behind the themes and embracing ideas and tensions that existed in the data, to add depth and detail.

3.3.2.3 Phase 6: Writing up.

Data extracts were selected to demonstrate the spread of themes in both an illustrative (descriptive) and analytic (interpretive) way, while also trying to achieve a good balance between the narrative and the extracts themselves. I spent time ‘dwelling’ with the data, constantly rereading and reflecting on my own “taken for granted thinking” (Ho et al., 2017, p. 1760). At the time of analysis, but not of data collection, I was working with cancer patients in the psycho-oncology department of a large London hospital and wondered about my own experiences, both as a cancer survivor and as a practitioner, in potentially influencing my understanding in the development of these themes. The reflexive element of this analysis meant theme generation was active and I was always aware of my centrality to their creative generation, and this entailed an iterative reflection on my place within the analysis, both with myself and with my supervisor, which is explored later.

There are 5 themes, each with 2 or 3 subthemes, listed here (Table B9), with a thematic map in the figure below (Figure B2). Braun and Clarke (2013) suggest that compelling quotations can work well to capture the essence of themes or subthemes, and this is the device used in this analysis.

Table B9

Theme list

Theme 1. Letting it land

Subtheme 1: Timing: “the last throw of the dice”

Subtheme 2: Priming: ”the jingling and the jangling”

Subtheme 3: Space and place: “like going from Tesco’s to Marks and Spencer’s”

Theme 2. Leaning into pain

Subtheme 1: Acknowledging the “fear monster”

Subtheme 2: Allowing the “tsunami of emotion”

Subtheme 3: Accepting the “mind shift”

Theme 3. Shared humanity

Subtheme 1: Suffering: “like a flower opening up”

Subtheme 2: Solidarity: “people that get where you are”

Subtheme 3: Support: “kindness feeds on itself”

Theme 4. Letting go of perfect

Subtheme 1: Being self-critical and shameful: “the horrible little voice.”

Subtheme 2: Giving permission: “the liberation of cancer”

Subtheme 3: Being fallible: “the ugly teddy, the broken plate, the wrong note”

Theme 5. Mindfulness (in)action

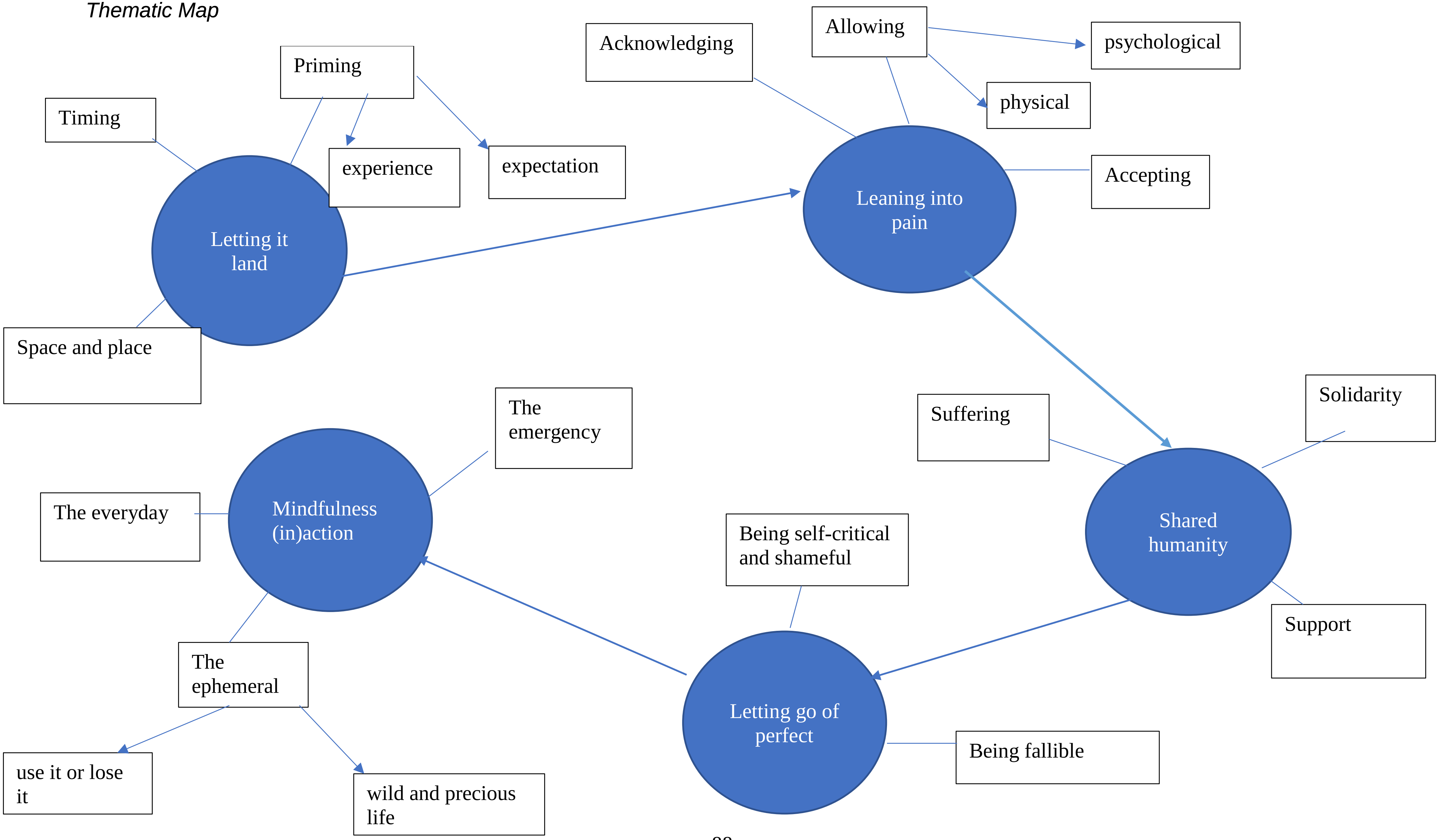
Subtheme 1: The everyday: “a way of life”

Subtheme 2: The emergency: “I coped with coronavirus”

Subtheme 3: The ephemeral: “my one wild and precious life”

Figure B2

Thematic Map



3.3.3 Theme 1. Letting it land

This overarching theme explores how most participants were open to mindfulness before they started the course. Participants frequently expressed frustration that they weren't getting the help they needed to manage their emotional reactions to their cancer and that they were struggling with negative, ruminative thinking, and catastrophizing. Anxious preoccupation, fatalism and helpless/hopelessness is reflected in the 'negative adjustment' subscale of the MACS, which shifted for most participants following the intervention. This theme suggests many had already recognized they were struggling to cope and were ready for change, believing mindfulness would help them relax and become calmer. Even those who were sceptical felt they would get something beneficial out of it and there was familiarity and trust in Maggie's Cancer Centres, as a place to try it.

3.3.3.1 Subtheme 1: Timing: "the last throw of the dice."

Participants often described a sense of isolation in trying to deal with their difficult feelings and not knowing where to turn. Henry, whose prostate cancer is incurable, was "a bit all over the place" and had tried counselling but it didn't work, describing it as "one complexity I just don't need at the moment":

"I sort of went to Maggie's Centre, having given them a call as the last throw of the dice because I couldn't think of what else to do …. the timing was quite fortuitous… I hoped that it would be helpful… I think it was something about trying to find some sort of inner calmness."

Henry seems aware of time running out, he knows his life is limited, and believes more counselling is of little value. Mindfulness is seen as a last resort and although he uses the word "fortuitous" about the timing of the course, he was already open to it and hoped that it would bring some peace where the complexity of cognitive approaches had not.

A similar sentiment is expressed by Maya, living with stage 3 cancer. She had a brief experience of mindfulness 15 years earlier and reports being back in a place: “where your mind doesn’t shut off and your heart’s in that pounding position again. So, erm, I thought it’d be really beneficial.” As with Henry, there is a view that difficult thoughts, sensations, and feelings are not being effectively tackled with cognitive approaches, or indeed, by any of her other techniques:

“I tried to use all my breathing and, you know erm, rationalization and evidence based and all these sorts of ...I’ve done CBT as well … those sorts of things. And just nothing, nothing touched it at all… I couldn’t even get into a place where I could think straight.”

Maya is aware that panic and pain affect her ability to think and notices somatic responses too. She observes her heart pounding and brain racing, which she has experienced before but now previous coping strategies are not working, there is a sense that desperation drives her to mindfulness:

“I just couldn’t shut off the negative thoughts. Er, I couldn’t sleep. Erm, I wasn’t eating…. I was in quite a lot of pain, so I was thinking that the pain would never go away and um I couldn’t cope with it, with the simplest of things. I thought my life had...there was no point anymore.”

For Maya and Henry, there is little risk in trying the mindfulness course because life seems hopeless, coping strategies are failing and time is running out. As Maya looks back on her reasons for enrolling on the course, she mentions an “overwhelming sadness.” Her treatment had ended but she was still in pain, feeling “completely numb” and “battered emotionally” and not “elated”, as she was anticipating. This sense of disappointment that life feels flat and devoid of pleasure, even when treatment stops, is echoed by others, like Jan, who began the course three months after surgery and describes being “so desperate, I really needed it … desperately, to be able to switch my mind off.” Most participants begin the course when their active treatment has finished, but Jan is still recovering from surgery and had just been signed off work. She acknowledges a high degree of ruminative thinking and believes mindfulness can “switch” it off. Lucy, meanwhile, is clear of cancer and has waited years before starting the course. She has a prior, albeit limited experience of it, and knows that it is a challenging process:

“There was always something pushing at me to do the mindfulness, because there was something saying ‘it’s time, it’s time, it’s time’… Finally, I was able to accept it, say ‘yes, okay, I’m prepared to go through it’. But before I was like, ‘oh, no, too much.’”

Lucy feels an inexorable pull towards mindfulness yet suggests it will take courage to face what it brings, and it took her some time to be able to do that. Whether participants are living with cancer, or beyond it, whether it is the perceived lack of time propelling them towards mindfulness, or a realisation that enough has passed to be able to face what it brings, for most participants, there is a sense of urgency propelling them towards it.

3.3.3.2. Subtheme 2: Priming: “the jingling and the jangling.”

Participants differed in how much they knew about mindfulness before it began, but a common theme was an expectation that it would help when little else had. Barbara, Jan, Maya, Tanya, and Henry, all hoped it would help them “relax” and become “calmer.” Emma heard it was “positive” thing to do. However, as Sam suggests, there was confusion, even scepticism, about what the course would entail:

“The sitting… doing all this meditation and the jingling and the jangling and the...((sigh)) ... it was just, yeah, very much a hippie-ish background of bells going and this going and that going...it was just something which was ‘out there’, which wasn’t me.”

There was a commonality among those who knew little about mindfulness, that it was somehow ‘other’ to them and a sense of surprise that they are trying it.

The initial impression of mindfulness was of something relaxing, mystical, spiritual, and for hippies, not an intervention that demanded practice, focus and discipline. Emma believed mindfulness had “some sort of Eastern belief behind it”, Tanya was “a little sceptical”, expecting a “semi-religious kind of movement” and Barbara thought she would experience “transcendental meditation, that we would go into a room and there was going to be this music…a little bit airy fairy… sort of floaty music.”

There was a general hesitancy among participants about what they would encounter, and some were keen to stress they were uncomfortable with the prospect of a focus on the self. Sally says: “I’m not kind of ((laughs)) ... I’m not really get into this sort of thing… I’ve never spent my life thinking about myself, really.” Sam echoes this: “I was ((sigh)) very cynical of things to deal with me. I’m not a person who likes to talk about me.”

While participants expected the course to help, it was noticeable how some were dismissive, almost apologetic, about talking or thinking about themselves; laughing it off or distancing themselves from it, and this discomfort with the thought of being the centre of attention or having to analyse themselves, is explored in more detail later.

3.3.3.3 Subtheme 3: Space and place: “like going from Tesco’s to Marks and Spencer’s.”

There may have been an initial reticence or wariness about what the course entailed, but participants were ready to try it and what gave them that confidence was knowing they had the time to give it, and that Maggie’s was a safe place to try it. Of the 10 participants interviewed, most were retired, or, like Jan, signed off work and financially stable, meaning: “I could take all the time …and just focus on myself and try to get better.” The course also offered a space away from the demands of family and hospital appointments, and Maggie’s was a familiar and trusted environment, as Emma recalls:

“Going into Maggie’s, it’s like, it’s for you, and it’s your time … and I knew, I knew it was a safe place to be as well. I had confidence in it. And I absolutely love it and umm, and you can go in there feeling any way you feel. And it doesn’t matter.”

Many participants like Emma had a prior experience of Maggie’s and knew it as a place where they could express themselves honestly and concentrate on their individual needs, and it is notable how many participants mention the word “safe” in connection with the environment there, as if contrasting it with the fear, threat and depersonalisation often experienced in a hospital setting. Talking about a recent incident in the chemotherapy clinic where she felt overlooked, Barbara says:

“We were just like numbers, you know. And I’ve always said to Maggie’s and they laugh at me and they said, ‘why do you like coming here?’ and I said 'Well, it’s like going from Tesco’s to Marks and Spencer’s'… if you go to Maggie’s, you go there as the individual, you’re having your treatment, but you get your tea, and people look at you and they can see that you’re not in a good way and have that time to... not ease your pain, because they can’t do that, but they have that time to just, let you talk about it. And that’s what I felt was missing.”

The supermarket comparison suggests it is about better quality or customer service, but participants also suggest it is about feeling heard and helped holistically, rather than being treated clinically and just seen as a hospital number. Barbara suggests that Maggie’s has a philosophy of offering time and space to those living with and beyond cancer, with people who are “well qualified…in that area.” It means she can finally raise an upsetting and deeply personal issue, that the side effects of the chemotherapy make it painful for her to go to the toilet:

“They had that holistic view of you as the person… I could probably talk to them more than even than my doctor about ‘hey, I’m having this awful discharge’ ....

But I would …. never done that to a nurse, you know, in the hospital who's supposed to be doing that as their job. That's strange, isn't it?"

Barbara queries why she cannot talk to a clinician about her side effects, but she can speak to a member of staff at the cancer centre, and this seems to be because the environment feels significantly different to her. Going to hospital is about getting treatment, a place where a patient is processed and managed. Maggie's is a different space and Barbara feels different as an individual within it, allowing her to reveal something more of herself.

Having a place of compassion, understanding and familiarity, and feeling, as Maya says that Maggie's was "a safe place…it wasn't like I was going somewhere unknown", also helps establish trust in the mindfulness teacher and the course itself, priming the participant to feel more secure about potentially showing their vulnerability. Sally says the mindfulness group rules, such as not agreeing or disagreeing with each other's views, offered additional safety:

"If someone cried or someone said something … people are not looking at each other and raising their eyebrows…it was a very non-judgemental space, which it's not normally in normal life." Being able to talk, without others commenting or offering solutions, feels more contained, with less room for judgement which may have been experienced elsewhere. The rules and structure of the mindfulness course means less room for potential disapproval, and this was especially important for those with a strong self-critical voice, which is discussed later.

3.3.4 Theme 2. Leaning into pain

If the expectation was that mindfulness was about "floaty" music, group therapy, or being taught how to relax, the reality was different and sometimes, difficult. Most participants came to the course feeling overwhelmed and overloaded, with a desire to stop, as Henry says; "all that shit flying around my brain", but few realised that acknowledging, accepting, and allowing for it, would be as challenging.

3.3.4.1. Subtheme 1: Acknowledging the “fear monster.”

Most participants live with the uncertainty of cancer, whether individuals are incurable and wonder whether they are “too advanced” for further treatment, like Henry, or they are experiencing pain which suggests “it’s coming back” like Maya or they are still being investigated, like Anna, who is living with uterine cancer, recovering from surgery, and now awaiting the results of a mammogram:

“Every time the post would come, I’d be sort of shaking because I think that … it’s going to be bad news … and sometimes you just get almost covered with this sort of almost paralyzing fear. …and the fear would… it would sort of write its own narrative…. I’m very good at the narrative…they are sort of long, involved and always end up with the doom and gloom scenario.”

“Which is what?”

“Umm, a very early death” ((long pause)).

Many participants, including Anna, express the fear of cancer recurrence and she later describes these thoughts and feelings as like living with a “fear monster”; a terrifying, internal enemy which takes over and which she can’t control. “The paralyzing fear” suggests a ‘freeze’ panic response, where rational thinking is impossible and where the body reacts physiologically to threat and danger. This apparently inescapable terror takes her, inevitably, to the worst-case scenario, that “they’re going to find a lump… and I’m going to have two cancers in two places.” The same, seemingly unstoppable catastrophic thinking, is true of Sally:

“((Sigh)) you know, in my, in my head, something’s happening, or something’s happened in real life and in my head, I’ve moved 20 stages on from that…the whole thing has already happened…your mind spins out of control, really.”

Sally, Anna, and many of the other participants recognize that the uncertainty of the disease returning prompts depressive and brooding rumination, which can seem unmanageable. The intention of a mindfulness intervention is to help identify this is happening, create a space to observe it, rather than be caught up in it, and perhaps feel more control in the process. Anna says that means paying attention to the “little voice” of uncertainty:

“If you don’t recognize it, then it’s doing its thing without you actually acknowledging that it could be making you more worried and erm…more stressed…I think with the mindfulness, it helps you stop and erm, just not let that narrative run away with itself.”

All participants, once encouraged to acknowledge difficulty, begin to realise how their thoughts, like Anna’s “little voice”, are attached to emotion and fused with behaviour and noticing this, not avoiding it, or pushing it away, is the first step to accepting and allowing it. Lucy talks about:

“The stuff at the back of your head, nagging at you, or going ‘listen to me’ …and so you say, ‘no. No, I’m not ready for you yet. Go away’. But eventually, it’ll come through, eventually it’ll force its way through somehow… I suppressed the anger for so long, it made me ill… my body turned on me… And it’s only after I accepted that, that I saw the anger and I looked at the anger and I understood it, that I started healing, I got better.”

Lucy refers to her body as absorbing all the negativity she felt unable to express and using it against her, like a friend who has now turned enemy. She is furious with her body for letting her down and when she engages with that anger, when she realises why it is there and believes herself entitled to it, she starts to “heal.” It is similar with Barbara who experiences painful reminders of her chemotherapy when she goes to the toilet; previously, she would have “this great British thing about, you know, pulling yourself together and stiff upper lip and all that” but as she acknowledges difficult thoughts during mindfulness, she also allows for the strong feelings which emerge with them:

“I found myself being very angry. You know, what…why? Why can’t I pee properly? Because it’s so, burn-y. And why can’t I go out to do number two? It’s awful…. there was an anger there about, well, I got all the treatments, and we ticked all the boxes, but nobody spoke about.... this is how you look after yourself afterwards. And that was what I think I'd been wrestling with."

In "finding" herself very angry, Barbara suggests it has taken her by surprise, but also acknowledges something valid and important; she was not told about the potential side effects and how to look after herself post-treatment and subsequently, when she failed to maintain her "stiff upper lip", she experienced a sense of failure and shame. Now, there is a rage attached to the injustice of not knowing that her experiences were to be expected and mindfulness allows her to see she has suppressed it. There seems an embarrassment attached to such personal pain and perhaps referring to it as "number two" and "peeing" minimises it and makes it easier to talk about. In the past, Barbara found it so difficult to connect with these difficult thoughts, feelings, and sensations, that she would become "Mrs Busy", trying to block them out:

"By suppressing them, I made them even more urgent and even more aggressive and even more umm…negative than they needed to be. Doing the mindfulness … I was able to step back and observe them… It's almost like re-education, isn't it? You know... the mindfulness is saying to you, look, this is what's happening… you've got to be kind to yourself, and you've got to go with the flow of it, because actually going against it, probably doesn't do your health much good... So that was the big change for me."

Being observing of thoughts, rather than fighting or avoiding them, is also mentioned by Lucy who says the process of mindfulness is: "like you're an actor, you know, like you're seeing a puppet, like performing on a stage" and this gives participants the distance they need to step back and acknowledge them. Emma says her ruminating thinking led to:

"Probably about five or six panic attacks where I literally passed out. I, I didn't realize initially they were panic attacks, and it was it was doing the mindfulness that, that, um, made me aware of, of what my brain was doing to my body. I didn’t realize that thoughts in the head could overwhelm your body, literally physically, erm overwhelm my body.”

This recognition of the importance of being both an active observer of what is going on in the mind and body and yet also being very present with the felt sense, helps participants on the mindfulness course connect their thoughts, feelings, sensations, and behaviours and this allows them to bring a compassion to their own physical and psychological reactions. Individuals are noticing thoughts and leaning towards the pain, but are doing this in a group and this, too can be revelatory, as Barbara says:

“It was the first time, probably ever, that I acknowledged that I did have these pains and things that felt quite damaged and not be upset about it, because other people have the same as myself. So, it wasn’t me being a hypochondriac. It was a result of the treatment. And the mindfulness taught me, to... ‘Yes, it’s there. No, this is not a cure for it. But just acknowledge it and be kind about it’”

The self-blame that Barbara refers to by using the word “hypochondriac”, suggests that prior to mindfulness, she was negating and minimising this pain, and allowing for it feels like a relief and a release. Like others, she is observing herself suffering and seeing others experience something similar helps her understand that being “damaged” is not her fault, but a consequence of treatment. This changes her reactions to cancer, encouraging the beginnings of self-kindness which is explored in more detail later. Most individuals saw an increase in their reported positive adjustment scores after the course, with Barbara witnessing the most clinically significant shift.

3.3.4.2. Subtheme 2: Allowing the “tsunami of emotion.”

Many participants said that leaning into pain, whether physical, psychological or both, was a tough and bruising process, and some wanted to give up. As Lucy said:

“There was a point where I was thinking ‘I don’t want to go back. I don’t think I can do this anymore because it’s just, it’s just too hard’. None of us wanted to face it actually. We all had difficulties and I noticed that some ladies went missing. So, it wasn’t just me ((laughs)). But I thought ‘no, you promised yourself you would do this mindfulness course and you’re going to stick to it…even if it’s painful, even it hurts. You will stick to this. You’re gonna fight it and you’re gonna stick with it’.”

“And?”

“And I did. And I felt better, so much better afterwards (mmm). It’s like, it’s my own battle… my own little war, I suppose.”

Here, Lucy must fight herself and her natural desire to flee, to stay with the difficulty and look at what is profoundly painful. She makes a pledge to “stick with it”, and although seeing others struggle helps her understand she is not alone and significantly shifts her negative coping style, it still hurts. Weeks four, five and six in the mindfulness course are about examining unpleasant experiences and noticing the reactions once participants connect with difficulties, bringing awareness to them and noticing how they turn up in the body. This focus was initially threatening for some, including Maya:

“I wanted to push it away and try and not to think about it. By thinking about it more, you know, my heart would start pounding. Erm. And then I’d say to myself, ‘it’s okay. It’s only your brain going into fight or flight, it’s’ … you know? ‘That’s quite normal. It’s okay’. And then, you know, very quickly, my heart stopped beating so fast.”

Understanding the cognitive model of cancer distress, which the course teaches in week four, and relating that to the physiology of what her body is doing in response to threat, helps Maya choose how she engages with that initial surge of adrenalin, where her heart is pumping. Like many on the course, she is living with acute pain from the side effects of the cancer treatment and being encouraged to lean into that was a huge challenge, initially: “The more I focused my breathing on that pain and distress, the more it intensified. So that was quite scary”, she says. However, Maya was in a safe group setting, with a teacher she trusted, who told them what to expect and it is that, and continuing the practice at home, which helps lessen the intensity of the pain and distress over time:

“The pain was still there, but it didn’t seem to affect everything that I did anymore… somehow that meditation, that concentrating on it, instead of trying to push it away … just being with it and accepting that…I was being kind to myself and saying, ‘it’s OK, it’s there’.”

The combination of continued practice, with an explanation of what is happening in the body and what might emerge from focusing on it, helps Maya turn towards and allow for difficult thoughts and feelings and report a meaningful change in her negative adjustment to cancer. Anna describes the process of change as acknowledging her:

“Tsunami of emotion or fear or just helplessness. Um, and I think probably before there would be the sense of drowning and I’m definitely going to drown. Um. Whereas now it’s the sense that, yes, there is the tsunami of this. But it’s going to wash over me and I’m going to bob up to the surface.”

Riding the waves of uncertainty, fear, doubt, and judgement is hard, but letting go of the struggle means that Anna can rise to the surface and not be pulled below. This realisation helps her understand that her distress is both temporary and survivable and allows for the development of self-kindness.

3.3.4.3. Subtheme 3: Accepting the “mind shift.”

There is a sense among participants that as well as acknowledging and allowing for the emotion, there is also a need for acceptance, that to live positively with the physical and psychological challenges that come with cancer, there needs to be a recognition of strategies which make pain and distress worse, and an acceptance of an alternative way of thinking and being, as Lucy says:

“Before it was just avoidance, it was just like…'Oh, can’t deal with it, not dealing with it' and just walk away. But d'you know, afterwards it was like… 'Face it. Deal with it. Move on.’ Because … I realize I can’t move on, I can’t move on until I deal with it, because it’s what’s blocking me, it’s what’s keeping me back ... But no, it was, it was good. It was, it was a shift, a shift I needed. I mean, it was sort of mind shift, if you see what I mean, it’s like erm, seeing it from a different angle.”

Lucy recognizes that avoidance kept her stuck, but observing her negative thinking allows her to distance herself from thoughts and see them differently, bringing a compassion to living with and beyond cancer, rather than ignoring or blocking them. This does not mean suffering and distress are eradicated, as Barbara says: “The pain hasn’t gone away, and the other after-effects haven’t gone away, but I’m not troubled like I was about them. It’s not a cure, but it’s an aid. It’s a fantastic aid”

Some participants, like Emma, Tanya, Barbara, and Sally say the body scan, introduced in the first week, provoked some of the most intense and surprising reactions. Emma becomes upset as she reflects on it, saying it was the first time “I had allowed myself to cry”:

“I got through the whole meditation. I hadn’t passed out … and it didn’t break me. I mean, I was exhausted, and I’d cried tons. But I survived it. And that was amazing because that meant that I could have some control ((sniffs)) … And I can see why it’s part of the course…because … it has changed me because I can cope, and I can manage. And it won’t break me. And looking back now, I hated it at the time, but it was so powerful, so powerful and....yeah. Really glad. Really, really glad I did it.”

“Hate” is a very powerful way of describing this process of leaning into suffering that Emma previously avoided or reacted to with panic attacks. The way that Emma and others describe the body scan and other aspects of the mindfulness intervention, is almost like an assault course, tackling the obstacles of sadness, anxiety, panic, and occasional flashbacks; initially hating it and becoming exhausted in the process but grateful to get through it and being proud of their strength and resilience at the end. Barbara orders herself to “face it”, Maya describes the body scan as “scary”, Tanya says it “affected her whole being” and Lucy says: “quite a few of the ladies were crying and were upset by it.” These participants are the ones who stayed the course, reported positive change, and chose to engage with this research, but all said it was initially frightening, intensely emotional, or physically draining and many were keen to stress it is not appropriate for all.

This shift in acknowledging, allowing, and accepting physical and psychological pain also takes weeks of group and home practice, as Emma says:

“The first few weeks, you’re thinking ‘Oh, really? … is this really it?’ … then you suddenly get like a light bulb moment of like ‘Oh, yeah!’ You can look back and you can see there has been a change in in your way of thinking. And it’s so clever, how it’s like a little drip, drip, drip from a tap. And it just sort of, you know, slowly, slowly leads you down that path, of …sort of enlightenment, really.”

The process of change, to Emma and others, feels as if they are being gently guided to a different place, and can now look back and see where and how the shifts in thinking and ways of behaviour have happened. During the course, with the intensity of the weekly meetings and daily practises, it was perhaps more difficult to identify that change, but reflecting on it allows participants to examine its purpose and effect.

3.3.5 Theme 3. Shared humanity

Initially, most participants say that when they began the course, they were reluctant to share their thoughts and feelings with others, either because they were too overloaded and overwhelmed with their own issues, or because they were fearful of pity. This theme explores how embracing the dynamics of a group environment became a key factor in participants’ perception of change in adjusting to their cancer and encouraged a shift in their rumination and fears of compassion from others, towards others and towards themselves.

3.3.5.1. Subtheme 1: Suffering: “like a flower opening up.”

Most participants joined the mindfulness course, not because they wanted to share experiences, but because they wanted to deal with their own difficult thoughts and feelings. As many had developed effective coping strategies of avoidance, withdrawal and suppression, the idea of being with others was initially, unappealing. As Maya says:

“I just wanted me to get better… in fact, I was thinking, ‘I hope nobody talks to me because I’m not interested’…I was completely self-focused… I was very self-centred. Erm. Nobody’s pain was as bad as mine. Nobody felt as awful as I did. Erm. Nobody understands…and I felt very alone.”

The reason for starting the course was self-interest and Maya remembers the loneliness of believing she was unique in her suffering and intense pain, which closed her off from other people. Others, like Sally, also believed a group setting would be threatening:

“I’ve never liked the idea of group therapy … I really don’t want to sit in a room full of people who’ve got all these problems the same as me. I’d rather not. I suppose this idea that it might magnify your own feelings. And as it turned out, I quite enjoyed that, actually.”

Sally appears surprised that she enjoys something that perhaps originally felt intimidating and exposing and this may be because she had an expectation that there would a sharing of a similarity in experience, which she didn’t want to engage in in case it made her feel worse. Perhaps she believed the course would be a different kind of therapeutic intervention, which involved more disclosure. At Maggie’s, the mindfulness course is described as helping individuals to acknowledge thoughts and feelings by focusing on the present moment, and is not supportive group therapy, which is offered elsewhere in the centre. However, some participants began the course believing that they would be expected to reveal painful details about their experiences and as many had developed coping strategies of avoidance and withdrawal, there was a hesitancy about engaging with others, as Emma says:

“I stopped talking to people because I didn’t want people to feel sorry for me and … I didn’t want to manage their, their emotions because I couldn’t even manage my own… I had to convince everyone that... I was fine and it was all going to be fine… and that just took so much energy out of me.”

Emma is so busy managing the expectations of herself and others, that she seems to become rigid and exhausted trying to prove she is coping. This is explored in more detail later, but it is notable how resistant participants were to the idea of revealing something about themselves which may encourage compassion from others, as Anna says:

“You don’t want to seem weak, um, and then it’s almost like as if someone’s being compassionate um, then it shows that there’s something wrong and there is … certainly a part of me that’s like ‘No, no, there’s nothing wrong…yeah. No, everything’s great’”

Accepting kindness means something is “wrong”, which threatens Anna’s sense of self, reminds her of her cancer status and makes her feel “weak.” Avoiding compassion and insisting things are “great”, makes her feel safer and more protected from their emotions and hers. However, once those on the course begin engaging with others, the threat seems to recede and many begin to feel differently about sharing their experiences about living with cancer, like Sam:

“I think ((sigh)) bringing up things was difficult at first, umm, with the cancer. I think when we talked about it, we all became very positive about our cancer, more than we were at the beginning. By the end, I think people were more accepting towards it…it didn't feel wrong. It felt right to be able to share, and them sharing with you."

As with many participants, Sam recognizes others suffer too and sharing experiences slowly leads to an acceptance of cancer, which encourages a new and more "positive" perception of life with the disease. The initial reluctance of disclosing difficulties shifts if they are endorsed by others, enabling the individual to create a different understanding of their reactions and the way they are coping with their cancer. A new meaning has been made in the process of hearing and being heard, where vulnerabilities are disclosed and validated in the group setting. Barbara echoes this change:

"One of the exercises was.... if there's something awful happening to you, can you recall how you dealt with it? And can you tell the others in the group? And I thought, 'oh ((sigh)) no, that's quite tough to share, you know, that you're not really coping with stuff'. But once I did that… I could see that there was the situation.... there was how I dealt with it, and I was actually acknowledging it by telling others."

Barbara externalises and observes the emotions felt in a difficult situation and allows others to see and acknowledge them too, which creates a sufficient distance to be able to accept them. Sam, who reported meaningful change in both depressive and brooding rumination says the course helped participants feel comfortable with sharing and this has benefits outside the group too:

"I think you feel like a flower; you open up during those weeks of talking and you know, togetherness … And I think it just opened up that avenue to say, 'well, you know, this is just a little meeting, but I have got a lot of friends out there who also I can open up to'. And I think that was it. Just sharing it within the meeting each week, getting better and better at doing it."

Sam and others are learning a new skill of acknowledging and accepting vulnerability, and by doing this in the group, it diminishes the threat of negative judgment and enables participants to reach out and talk to those outside, increasing their circle of support and reducing isolating, ruminative thinking. The image of the flower, opening from a tight bud to a full bloom, suggests beauty and growth in the recognition of fragility and a positive feedback loop for the individual of connecting with others to share it, which becomes easier as time goes on.

3.3.5.2. Subtheme 2: Solidarity: “people that get where you are.”

A major part of the positive shift in adjusting to cancer for many participants and what seems to change their negative thinking, is not only the sharing of their own suffering, but recognizing they are far from alone in their pain and this helps create a sense of community and compassion. Henry says this was as important in shifting his feelings of depressive rumination, as the meditative exercises:

“Every conversation that you started, you had this sort of feeling of ‘we’re all on the same page,’ you know, ‘we’re in the same team. We understand each other.’ So, there was something that I think was very important in feeling that you’re going some through some sort of an experience together, with people that get where you are.”

Henry is typical of other participants in believing that the group element of the mindfulness intervention, engaging outwardly with others who are on a similar path and who understand you, was as important as the self-examination, or looking inward. These internal and external processes happen concurrently, and are inextricably linked, working together to better effect. Maya agrees that it has been crucial to her experience of change in ruminative thinking and her perception of living with cancer, to be with people who are “going through the same things as you.” She also recognizes that some on the course are “worse off than me” and this comparison helps Maya put her own suffering in perspective. Sam endorses this, saying what she got from the meetings was that: “there’s always somebody worse off than you.” Henry, who has a prognosis of around six years, describes a rush of compassion towards another man with prostate cancer, who has suddenly deteriorated: “Maybe it was a survivor’s guilt, that at that stage I thought I was in a better place than he was?”

Seeing those whose cancer is more progressive, helps participants feel kindness towards them and this may also alleviate some of their own pain. Within the group, discussing similar situations while recognizing differences, also allows for self-compassion and expressing compassion for others. As Sam says:

“Just working through those situations…er… together and laughing about it really and having that little bit of connection…each one of us had a different story to tell on their cancer and their situation and their families. And I think, basically, we were all very much of a likeness that...we didn’t give time for ourselves.”

Finding humour in difficult circumstances helps with bonding, seeming to act as a buffer to anxiety and working as an effective coping mechanism. For Barbara, the laughter comes in acknowledging she is not alone in struggling with some of the aspects of the course, or with her difficult thought processes around her side effects:

“When we were talking about what do we expect from mindfulness, you know, all these funny things sort of came out umm, about how we were feeling about ourselves… that was quite a nice thing to realize that people were, were the same, you know it wasn’t just me, who was feeling, well, what about all this after-stuff? Lots of people were trying to manage it, but not succeeding.”

Towards the end of the eight-week course, around week six, there was a retreat day, where participants are asked to remain silent. As many were enjoying discussing their shared experiences, the idea of a day without talking proved challenging for some, like Tanya:

“((Laughs)) All day, I thought, ‘no, no, this is I’m not sure this is right. You know, is it going to work for me, am I going to get really frustrated by not speaking?’ And, actually, it was such an interesting experience. We did mindful eating. We did mindful movement … but as individuals in our own space, sharing it and…and finding that peace within a group and being able to come back and share that together at the end was really interesting."

A day without noise helps Tanya and other participants bring the concept of being mindfully present to everyday activities like moving and eating, and this encourages a sense that mindfulness can be more than meditation or reflecting with others. Although participants spoke about a connectedness through speech, this was a shared quietude, bringing with it a sense of peace and perhaps, an understanding that the skill of focusing on the 'here and now' is felt within the group and beyond it too. It was at once, an experience they embraced together, yet also enjoyed as an individual. As Anna recalls:

"The day's retreat was just amazing. I just found... that brilliant and …I can still think back to that feeling when we were all kind of there together, eating in silence and doing these sorts of practices in silence. I can think back to that feeling and … holding on to that feeling, that, I found quite comforting."

For Anna and many participants, trying this new, silent experience together bolsters the community feeling, but for Sally, the retreat day is also about taking the pressure off herself: "I felt liberated… I don't have any obligations; I don't have to do things. It's just me that I have to be responsible for." The process of the interview allows her to further reflect on why the retreat day felt so positive: "Thinking this out with you is very useful, actually…. it's as if I have to give myself permission. And here, there is no need to give permission."

Sally realizes that the retreat day gave her "permission" not to manage others, or to achieve, and this feels like freedom. Yet, while describing this, she questions why she must earn, authorise, or allow herself this time. Sally is not used to self-care; putting others first is so ingrained and automatic, that it comes as a surprise to realise that she deserves this kindness to herself, and this is explored in the next main theme.

3.3.5.3. Subtheme 3: Support: “kindness feeds on itself.”

Many participants talk about a reciprocity of kindness, that if one is kind to others, it extends to accepting it from them too, and showing it to the self. However, sometimes the giving of compassion feels easier than accepting it. Henry describes encouraging a fellow group member to stay on the course, when she was thinking of dropping out: “I was trying to say, ‘no, no, come on, stay. Stay with us a bit. We’re all part of this group. Stay with us’. And she did.” This is part of what Henry calls “being on the same team”, yet when he describes accepting kindness from others, it appears harder. Realising that his cancer had returned and was incurable, he did not want to disclose it because he wasn’t sure “how to handle people knowing.” He confides to the rector of his local church, who comes to see him in hospital. The following Sunday, the rector tells the congregation and initially, Henry says he is furious, believing it to be a “breach of data protection” and thinking “how dare he tell people!” However, once he takes time to reflect, he realises, “actually, that was an incredibly kind gift, because he has taken away from me the burden of ‘how do I manage to talk to people about it?’ Because people are coming up to me with massive kindness.” It is this, along with a book he is reading about a minister on a holy pilgrimage, who encounters both unexpected difficulties and kindnesses, which helps Henry acknowledge the “gift” of compassion.

It is difficult to pinpoint what makes the difference and Henry acknowledges he cannot “quantify the impact of the individual elements. I’ve just got to be grateful that the way the rector handled the news, the book, the mindfulness course, that it’s all come together and helps me into a more, more positive and hopefully, kinder place.” Henry can show compassion to others, but it took longer to accept it. It is an act of kindness from someone he trusts, which sparks further kindness from the church community and this, together with the book, helps Henry move towards this more “positive” and “kinder” place. It is almost as though he is making his own spiritual pilgrimage in understanding the universality of suffering and grace, with mindfulness just one of the elements that helps him along the way. Sam, like Henry, was initially more comfortable with dealing with difficulty alone, believing that accepting compassion is unnecessary. However, a recent upsetting, personal event makes her question her previous coping strategy:

“I lost two friends on the same day last Monday…. Before I would have hid that, I would have buried it and said, 'I’m fine, everything’s okay…I don’t need it. I don’t need compassion. I don’t need kindness.’ But I put it out there.... and I think just realizing that people do care…and generally want to want to know … just sharing it, erm, it just it just made me feel a lot lighter.”

All participants seemed to begin the course with some sense of isolation, burying rather than sharing their difficult feelings and it takes time to be able to accept kindness from others and recognize they genuinely care. The “lightness” that Sam describes, is letting go of a load she was used to carrying alone. The more she does it, the easier it becomes, the lighter she feels. This incremental change and shift in giving and accepting kindness is also seen by Maya, who initially “didn’t think of anybody else at all” but who realises that she is more able to cope with her own feelings and to feel less lonely when she extends small acts of compassion to another member of the group:

“I suddenly thought, ‘Oh! I must be feeling better because I’ve just asked Laura does she want to go swimming! And that’s a really nice thing to do. And I haven’t done anything really nice for anybody, you know, for a long time.’ So, it really, really stopped me… and I suddenly thought, ‘Oh! It’s coming back! I’m getting better.’ So, it’s like somebody had switched a light switch on.”

A light is turned on and a load lifted after the experience of accepting or expressing compassion, which suggests previously, troubles felt darker and heavier. Many participants, like Lucy, describe losing the ability to be compassionate during the cancer experience and that the course helped her reconnect with the idea of the commonality of suffering, which allows for an extension of kindness to others and to feel better about herself. She recognizes limitations to this though, saying she could:

“Do compassion to myself and maybe…to my dog and my brother and my sister…but not really to the whole of humanity. I mean…I know I should have done, but I didn’t! ((laughs)).”

Despite her reservations, of all the participants who reported a shift in fear of expressing compassion for others or in responding to the expression of kindness from others, only Lucy showed a meaningful change in both scores. One of the kindness meditations is extending compassion towards yourself, to someone you like, to someone you dislike and the rest of the world. To those with cancer, it is perhaps understandable that they might find compassion easier to accept and to give within the group, with others having similar disease experiences. Some participants expressed anger about the medicalisation of the hospital process and the reactions of those friends and family without the disease, which is explored in the next theme, and this may stand in the way of them extending compassion more widely.

3.3.6 Theme 4. Letting go of perfect

What often seems to get in the way of participants accepting compassion from others or showing it towards themselves, is a perception that they need to be seen to be managing their cancer ‘well’ and as Maya says, this means “pretending and putting a face on for everyone.” This theme examines how mindfulness helped participants recognize where this self-critical voice comes from, how it drives their need to be seen as ‘coping’ and how they respond to it. It looks at accepting fallibility and feeling deserving of self-kindness, which proves harder for some, than for others and it reflects on the issue of shame.

3.3.6.1 Subtheme 1: Being self-critical and shameful: “the horrible little voice.”

Many participants appeared to live with a harsh, internal voice that existed before the cancer diagnosis, and which influences how they think and behave after it. Sally says that being judgmental “is a fundamental part of me” and puts this down to what her mother used to tell her:

“She said, ‘well, you might be top of the class now in the junior school. But just get to that grammar school!’ And then … ‘well, you might be top of the class at the grammar school, but just wait until you get your first job! And then you’ll find out.’ So people end up their whole lives waiting for the point at which they’re not good at something … But, you know, you could have become, I don’t know, a prima ballerina or something. But actually, ‘just wait until you fall off that stage!’”

It is this deeply ingrained and long-standing fear of not being “good enough” which affects the way individuals respond to challenges like cancer. Barbara believes that many on her course had: “very harsh mums who bring their children up to, you know, get on with life and just...no compassion at all. Don’t even want to talk about it. Don’t ask you how you are. Whatever you’ve got wrong with you, it’s worse for them, even though it’s cancer ((laughs)).”

The developmental impact of being brought up in an environment where compassion has not been modelled and where individuals are expected to be selfless and uncomplaining, means it can be difficult for individuals to accept kindness or show it to themselves, even if they are in great pain. Sally, who is recovering from surgery, chemotherapy, radiotherapy and is on hormonal treatment, thinks she should put herself ”at the back of the queue”; Barbara, with acute side effects, says it’s about “not bothering anyone”, Sam, whose cancer is incurable, says being described as “backward” at school, means she “criticized myself a lot” and equated self-care with “selfishness.” It is the same with Lucy, who realises after completing the mindfulness course, that her long-standing, internal, criticizing voice belongs to someone else:

“It’s only afterwards I realized that the negativity wasn’t necessarily my voice, it was someone else’s voice… you know, like your parents and your teachers… it was just like; ‘you’re not good enough. You’re not good enough. You’re not good enough.’”

Mindfulness helps many participants acknowledge and externalise the “not good enough” voice, placing it back in the past and with others, which allows for self-compassion. When Barbara’s voice says she is “focusing too much on yourself and you should be able to go back to normal”, she asks herself what “normal” means in the context of a cancer experience and this helps her challenge a life-long script that told her that a focus on the self is indulgent and wrong, and that virtue lies in coping and being busy. Anna describes “bottling it up” and “being normal” with her work colleagues, as they make comments like:

“’Wow, you look amazing! Oh, what have you done? Is it available on the NHS?’ And I’m just like laughing. The irony of it. ‘Yeah, just pop along to the Marsden and get some radiotherapy’... And then I think there’s this pessimistic voice that says, erm yeah, you know, it’s like ‘don’t know if you’re going to be here next year.’“

Anna struggles with this duality of self, the perception of the ‘healthy’ self and the one who has just come out of surgery for uterine cancer. The “voice”, like many other participants, reminds her of her disease, even as she is being praised for “looking amazing.” She knows that it is a consequence of cancer treatment and a reminder that she is living with disease, which makes her try even harder to prove she is coping:

“I felt that if you aren’t always sort of on top of things … that means you’re a kind of a failure that you’re not.... actually, dealing with it as well as you perhaps ought to be, or people think you are.”

Many participants recognize during the mindfulness course that life with cancer is, as Jan says, filled with a lot of "shoulds" meaning when "the going got tough…I kept digging deeper." Self-care can suggest weakness, selfishness, self-indulgence, or failure. Emma, who was having panic attacks before she began the course, says: "I really hated myself and really gave myself a hard time and really beat, beat, beat myself up." She would start "a million jobs" to show she was "really strong" but didn't have the energy to complete them:

"I always felt a failure because I … I hadn't met all the … demands that I put on myself…thinking I had to do everything and be everything …to try and make people understand that I was okay ((laugh)). And ...just if I did everything and I was everything and I could do everything, erm, then I would be fine."

Emma, Jan, Barbara, Sally, Anna, and Sam all become exhausted trying to "do" and "be" everything, to prove they are "fine." Part of this is to maintain the identity they had before cancer and dismiss the worries of others, but it is also to show *themselves* they remain that person too. The mindfulness course helps Emma recognize and acknowledge this:

"I identify that now... that I am harsh on myself, and I do really like myself. I'm much calmer. I don't panic as much. I don't go to a million miles an hour. I also identify that I don't have to keep filling my life with jobs to get through the day … I'm much nicer to be around now. Although I didn't think I was being horrible or mean. I was just frantic and impatient."

Many participants observe this state of impatient freneticism as they try to get back to their previous, "healthy" identity. Barbara describes the "vortex" of busy, which can suck her in and down until she is "so worn out, I fall asleep." Yet she also associates fatigue with her grandparents who slept in the afternoon, thinking; "Oh God, you know. I'm getting so old, so quickly." Trying to keep awake doesn't work, yet sleeping reminds her of illness, perhaps her own mortality, forcing her to get back up and get busy again. As she talks about mindfulness helping her to feel "ok" about resting when she is tired, she also recognizes a shift after being told that one of the side effects of her radiotherapy treatment is fatigue, which gives her “permission” to rest:

“Although I slept, it was acceptable. That’s funny, isn’t it? I’ve just thought about that. Yeah, it was acceptable because I’d been told about it….and then you make a little mental note to be kind.”

The side effects of cancer can be debilitating and can affect participants physically and psychologically, after the ‘active’ treatment is considered over. Some are recovering from surgery, others are on hormonal treatment and the exhaustion, side effects and mood swings that can result, adds to a sense of shame that individuals are not coping as expected, and as a reminder of their previous “healthy” self. Barbara struggles to be kind when she describes “not being able to pee properly” because of the side effects of the chemotherapy, which is “a horrid thing” and something “so private, you can’t allow yourself to be compassionate about it.” She cries when she describes the intimate and “embarrassing” details of her treatment and is not sure whether mindfulness “really touches that, but it helps to acknowledge it…it’s helped me to be honest.” Of all the participants, Barbara is the only one who saw her fear of self-compassion rise significantly after the course and perhaps this goes some way to explaining why.

Many participants believe the course has helped them notice how entrenched their critical voice is and how it has prevented self-kindness, but they also recognize that deep-rooted emotions like shame or grief can be hard to challenge and change. Sally sees cancer as a threat to her understanding of herself and becomes tearful when talking about the “indefinable loss” of her past, healthy “resilient” self:

“I think it was the idea that why were people constantly asking you how you feel? You know...there must be something wrong with you… I don’t want to be this person who people have to ask how I am…. you feel that something’s been removed from yourself, or your personalities changed in some way. Isn't it weird? I'm feeling a bit tearful again. I don't know why? It's just...ummm... ((voice cracks)) weird, isn't it?"

Being changed, perceiving herself as somehow lesser, is hard for Sally to manage and, like Barbara, the process of the interview has redirected her attention onto this pre-cancer/post-cancer identity. She seems taken aback by the sudden rush of emotion when talking about her life before and after, and although she understands that the "intellectual" part of mindfulness is about saying "don't judge yourself…you know, it doesn't matter", she struggles to truly embrace it:

"Self-kindness... being kind to myself, I equate with selfishness … I mean ... you don't have a session of mindfulness or a course of mindfulness and then find that something's changed. And some things I think have changed, definitely. But I …I don't know that it's helped me to be able to do what I want to do, necessarily, without some struggle … I don't think it gave me the tools to stop criticizing myself."

Sally's "not-good-enough" script, learned as a girl, has stayed with her and she is aware of the limitations of mindfulness in changing a lifetime of driving, striving, judging, and denying herself kindness. However, there is a sense among participants that they are, perhaps for the first time, recognizing and observing the critical voice and what it has been doing to them. Maya says when she was diagnosed with cancer, it felt like she had a "horrible little person" on her shoulder, telling her she was "miserable and useless." It made her stop doing the things she loved:

"I lost part of myself. That's what the cancer did to me. It robbed me of me, because it took all my energy to... just to function. So, because, you know, everybody is made up of lots of different things, the way you are with your husband or your children, you know, a Mum or a teacher or a, you know, they're all like little bits of you, aren't they? And I'd lost all those bits. And I'm slowly putting all those bits back."

Maya describes her life now, as spending time with her daughter, baking cakes for the village, making masks to give away for the pandemic and going back to work part-time and she appears to be reclaiming those “bits” of herself, the mother, the worker, and the helper. She no longer feels defined by her cancer status and she credits the course with giving her the confidence to accept her disease and welcome the other “bits” back. Mindfulness gives participants the ability to observe *all* the bits of themselves, even the harsh, judgmental voice. As Emma says: “it doesn’t nag me as much. And equally, when it does talk to me, I identify it as my critical voice.”

3.3.6.2. Subtheme 2: Giving permission: “the liberation of cancer.”

While some participants felt cancer robbed them of a part of themselves, others believed it finally gave them permission to be looked after and feel nurtured in a way they hadn’t felt previously. Jan says: “It was a relief getting ill…you don’t worry about the smaller things; you just have to worry about yourself and getting better. There’s no expectations of what you should be doing with your life.”

Sally echoes this idea of cancer removing the expectations of others and herself, by allowing her to “relinquish responsibility for everyone else’s wellbeing” and reflecting on this upsets her:

“I think it was the first time in my life when I’d ever been able to, been allowed… allowed myself to think about me and nobody else ((voice breaks)). ((Pause)). So, it was kind of …it’s weird really, isn’t it? So, if I just wanted to go to bed in the afternoon, I didn’t have to think of .... this is ridiculous.... I just went to bed in the afternoon...so that was one thing which I enjoyed. …it was liberating in some ways.”

That participants feel cancer is a “liberation” and “a relief” because it allows them, finally, to concentrate on themselves can seem, as Sally says, “ridiculous.” The realisation that she didn’t need to “think of” something to allow her to rest, and that the disease is to be welcomed because it gives her permission to look after herself, comes as a shock to her. Sometimes it is unclear whether it is the disease which has helped individuals shift their perspective, or mindfulness, or a combination of both, but having an hour to go to the mindfulness course and time to practice at home, appears to have helped individuals become aware and then indicate to others, that they are deserving of self-care. Sam, whose breast cancer has spread to her bones and her liver, says it is about:

"Those moments during the day where you can actually say, 'this is about me and you's can all go and, you know, do your own thing. You're old enough, you're big enough.' And I need that time… you know it was teaching you to sort of do that breathing and take that step back and listen to yourself and think, 'I need this hour to myself.'"

The existence of the mindfulness course and its structured approach of home and group study, helps participants reclaim this time to themselves without excuse or apology. It also encourages them to let go of what they expect from others, as Jan says: "I expect less from other people. Yeah. I let people be themselves and …. umm, what's the word? Take responsibility for themselves."

Participants like Jan and Emma say doing this is a "continual path and process" and some recognize their instinctive guilt in accepting the need for self-care. Anna, who has uterine cancer, initially makes light of it:

"'I'm doing all me, me, me, I'm having my reflexology, I'm having a facial. I'm you know, it's all about me… And part of it is a joke…. but I think it is important … and I will say this to other people, um and now, I think I'm actually doing it for myself and not feeling guilty about it either."

Through the mindfulness, Anna realises she doesn't need permission to care for herself and can let go of that guilt, but saying that she is "actually doing it for myself" suggests that previously, she may not have been. Now, she believes she is entitled to it. Jan also says the course helped her to look after herself while "not feeling guilty” and Lucy agrees, saying self-compassion is also about being able to accept that: “I deserve it… yes, I am worthy, I am worthy… that sense of worthlessness has gone… If people want to praise me or give me something… before I was blocking people. It’s like running away, isn’t it?”

When comparing how Lucy thought of herself before the course and what she thinks now, she says: “I actually like myself. There are lots of things about me that I actually like … ((laughs)) I know it sounds a bit weird, doesn’t it?” Even while acknowledging their worth and value, participants are sometimes self-deprecating, second-guessing how others may perceive them, if they admit they like themselves.

3.3.6.3. Subtheme 3: Being fallible “the ugly teddy, the broken plate, the wrong note.”

A large part of recognizing self-kindness for Jan is “accepting that I make mistakes. That I’m fallible. I’m not as much of a control freak as I thought I was.” Being deserving, letting go of control and acknowledging mistakes, helps shift many participants’ perspective on themselves, their thoughts and feelings, their relationship with cancer and their ability to give and receive kindness. Jan tells a story about her sister who, when visiting after surgery, calls her as a “poor, broken sister.” Previously, this would have felt hurtful, now she reflects that being “broken” feels different:

“I remember I embraced it, as in, it’s like when you’re performing, like a musician and doing a performance. You always worry about playing the wrong notes, and once you’ve … played one or two wrong notes, you don’t worry about it anymore, it happens and it’s not the end of the world… in an improvisation… there’s no such thing as a wrong note really.”

Jan, a musician, turns “broken” into something creative and wonderful, as in music, where a “wrong note” can inspire change. Sam’s love is knitting and even there, mindfulness helps her reframe what is good and bad, right, and wrong:

“I knit a teddy bear the other day and straight away I was like, ‘ooh, that’s an ugly looking teddy bear!’ ((laughs)) but I … I sort of thought, ‘well, you know, somebody will love it’... before I would sort of...’Oh, throw it away!’ … but now it was like ‘it’s not too bad’….and I think it’s little things like that that I’ve noticed in myself that I don’t criticize myself as much for.”

Embracing the beauty in the different and reframing life to ease off on rigidity and control, brings a new perspective to living with cancer. Jan describes mindfulness as helping her let go of “perfect”:

“Like you’ve got a plate that you really, really like, that’s in perfect condition and you drop it, and it breaks? Umm…and you can fix it, glue it back together…yeah. I feel like I’m actually better than I was before… like that programme called ‘The Repair Shop’, where they fix things, you know, old things that have been broken and … make them, make them good again? Good as new, really.”

Many participants recognize that they are in a process of putting themselves back together, where they feel stronger and more resilient than before. Part of this is about reconnecting with enjoyable, daily activities they may previously have avoided. The course asks individuals to view an activity mindfully and think back on a pleasant event and to use a ‘pause’ exercise in daily life. For many, this pause helps them to step away from the freneticism described earlier and reminds them of the joy and connection in quiet, everyday experiences. For Maya, it’s an apple pie, baked for her husband, the first since recovering from surgery:

“He said to me, ‘that was the best apple pie I’ve ever had.’ And I said ‘Darling, I don’t think so, I’ve made apple pie before, I don’t think...’ He said, ‘No, no. That was the best one.’ And it was the first one that I’d made…. so, all those sorts of things. Yeah. Yeah.”

Whether it’s an apple pie, a repaired plate, an “ugly” teddy, or an improvised “wrong” note, individuals begin to see the value in being a little kinder to themselves, noticing the small triumphs and letting go of failure, fault-finding and shame and blame. For Sam:

"It means…not, not feeling that it's my fault. Erm. And trying to sort of foster an inner warmth or.... erm, like a sort of a soft stone that you can … rub, that gives a little bit of heat when you when you rub it, and it feels nice and just the right size in your hands? Kindness to me seems warm … and erm, nurturing… like a physical thing that you can actually almost touch."

Kindness and warmth to Sam and to many other participants means relinquishing unrealistic expectations, control, and the idea of the "right" way to live with and beyond cancer and this feels "right" and comforting. Emma notices the change in herself when she allows her husband to buy her an expensive handbag:

"It was like a change for me.... I just wouldn't let anyone buy me anything... I was so fearful that life was going to end. But it's, yeah, it's lovely. And I love my handbag…and it makes me smile when I see it ((laughs)). Yes. Yes."

Accepting her husband's gift meant acknowledging previous catastrophizing and rumination and accepting the here and now, and his compassion made her feel "loved and precious and treasured." Emma and her husband run their own business and are cautious with money, so allowing herself to have it, without chastising herself about the cost, was an act of self-kindness as well as demonstrably accepting it too. For most, like Emma, the mindfulness intervention helped re-establish a sense of self-worth which makes it easier to accept compassion from others. Tanya is reminded of this in her surgeon's office:

"It was one of the checks and everything's absolutely fine. And I said, 'Oh, you've got …bigger fish to fry.' He said, 'No, you're the big fish' ((laughs)). But he was right, wasn't he? You know, you're the fish."

Tanya initially diminishes her value, echoing the other participants' belief of not being a priority. Only once she is reminded of her importance, does she question her initial assumptions and give herself the value she deserves. She is not saying that “mindfulness has eradicated everything”, however it has helped her realise that “I should think more about myself.” As Lucy says:

“I didn’t really realize until … after mindfulness of how hard I was on myself actually. It’s like a load has been lightened. It’s like… a door had been opened… or a window had been opened. It was like umm, it wasn’t a great revelation, but it was sort of, a sort of a kind of a ((sigh)). I’m here. I’m where I should be, I think. ((Mmm)) Yeah, this is the real me.”

Lucy echoes Sam when she describes feeling “lighter” and others too believe mindfulness has made them more congruent, allows them to be more like themselves and reminds them perhaps of what they already know, that sharing can help alleviate the burden and accepting compassion from others is not a weakness but can open the door to further support and healing. For many participants, pain and distress are reminders of the disease and it is still a work in progress to accept that kindness. Barbara, whose “horrid” side effects created a sense of deep shame and anger that prevented self-compassion, seems more able to accept kindness from others than show it to herself. Before mindfulness, she says she could not share her feelings with her husband: “It was just like ((gasps)) ‘you know this is my womanhood’. Just... I don’t mind about the cancer, but I do mind about all these things.” However, since she began sharing within the group, she also started talking to her husband, who is now accompanying her to hospital:

“And then, usually …((laughs)) what do they usually say? ‘Well, it’s those women’s things!’ (laughs). He shares it. Yeah. Yeah. Yes. It’s opened up so much more than I thought it would, mindfulness, it wasn’t just about learning to relax ((laughs)) and having your nice floaty music.”

Barbara’s initial expectations of mindfulness have been confounded. It is harder work than she thought, often more painful, but by the end, she acknowledges the strong emotions of anger and shame, which accompany her suffering. The emotional and physical pain and sensations are still there, and her struggle with accepting them continues, but she feels able to share this with her husband. There may still be some embarrassment, perhaps from them both, about discussing “women’s things”, but he is alongside her as she goes through it.

3.3.7 Theme 5: Mindfulness (in)action

Mindfulness is a skill which many participants, including Jan, say is now “infused into everything…part of my every day.” Some say it has become a tool, used almost unconsciously, and woven into other activities like gardening, painting, or weaving. Many say they also use it for emergencies, such as before surgery and during the first coronavirus lockdown, which had just started as these interviews began. This theme also explores the tension between ‘doing’ and ‘being’, allowing things to be as they are, rather than pursuing or achieving. While mindfulness is seen as an active process, it has more to do with grounding, calming, and accepting; going beyond what they traditionally thought of as ‘practise’ and changing their perspective on life and living with cancer.

3.3.7.1. Subtheme 1: The everyday: “a way of life.”

The eight-week mindfulness was intensive for participants, who were also required to do around 30 minutes of home practice a day and read the supplementary literature. The interviews were conducted between one and four weeks after the course had ended and while most said they were now not adhering to regular daily meditative practise, they felt they had learned a lifetime skill which showed itself in other ways. As Barbara says:

“It’s become a way of life...it’s like learning to read, really…you start off with one alphabet letter and then two or three and then you put it all together. And then in the end it just becomes like...you know, it just becomes nice and smooth, so, you don’t even think about it.”

Mindfulness is now so emmeshed in Barbara’s way of being in the world, that it comes without consciously thinking of it, but this took time to learn. For Tanya, the skill of leaning into thoughts and feelings, rather than avoiding them, has also helped shift her brooding, ruminative thinking but again, she recognizes that this skill needed effort and attention to develop and maintain:

“It’s like learning a language … you have to keep at it for a long time for it to stick. And of course, I still ((laughs)) I still ruminate at times, but it’s less and less…it’s not a conscious thing? … I’m not thinking, ‘Oh, right, I must look at this list to make sure that I’m doing this, this and this today to stop ruminating’, it’s becoming sort of natural, you know, it’s becoming part of me.”

Mindfulness shows itself in ways other than body scans and attentional breathing; it is infused in participants’ life, such that they don’t feel the need to tick a box or cross an activity off a list, to prove to themselves that they are being “mindful.” As Tanya reflects, it is an integral part of who they are and woven into everyday activities: “The mindful gardening ((laughs)) … I mean I must be crazy. I love weeding because I find it...I’ve always found it quite meditative really because you’re pulling up things up… it’s so fulfilling.”

Perhaps Tanya is pulling up her own ruminative weeds, or perhaps it is simply that she is recognising activities that are beneficial to her, which also involve some contemplative awareness which prevent the brooding. Mindfulness is, she says, just “a label” attached to a new skill, practice, or knowledge but which for her, and others now “comes naturally”:

“I have the ability to do something now that I couldn’t do before. And I don’t know why I couldn’t do it before because I knew, I knew that breathing deeply was a good practice… in theory, I knew these things. But in practice, I wasn’t doing them! ((laughs)).”

It is notable how some participants believe this understanding was implicitly there, waiting to be uncovered and explored with the help of a teacher, a group, some direction, and a lot of practise. It is this combination which helps remind Tanya that the breath, which can nurture and nourish, is always with her. Anna practiced the breathing exercise until “it became sort of second nature” and this means she feels confident to use it, and other exercises, more flexibly:

“Suddenly if you find yourself in a stressful situation… you can’t just like ‘right, I’d better, just lay out on the floor for half an hour or whatever’ but that you can use that sort of; ‘right, just a few moments.’”

Mindfulness doesn’t have to be sitting or lying down for long periods of time, participants make it their everyday by acknowledging a breath, or gardening, or painting, or for Henry, weaving, which is as a meditative practice for him. However, Henry recently “hit some sort of crisis” where he “just seemed to lose it a wee bit” and can’t identify why. He believes he is coming out of it and “getting back a little bit into reading and into mindfulness meditations again… I haven’t got back into weaving again, but I feel I’m sort of getting there.”

It’s important to note that for Henry and others, mindfulness and the benefits from it are not necessarily, as he says: “a straight linear thing. It’s this sort of roller coaster journey.” Although the participants here perceived change, they also experienced knocks and blocks along the way, whether related to the cancer, or the course, or, like Henry who was going through relationship difficulties, something else in their life and this is explored in more detail in the final subtheme.

3.3.7.2. Subtheme 2: The emergency: “I coped with coronavirus.”

Mindfulness practice help most participants deal with crises, including Tanya, whose bowel and liver cancer is incurable. In recent surgery, she feared the operation would “take a much larger section of my liver away” and began to catastrophise about not surviving it. Tanya talks about this being a “test” of mindfulness, seeing whether it would shift challenging and upsetting thoughts and feelings and while she recalls this, she becomes upset:

“This last surgery is the first time that I felt scared… ((sniffs)) but mindfulness came to the rescue ((pause, cries)). And I thought again, this is fate. And there’s a little mantra that I just said to myself and it’s ((sniff)) ‘May I be safe ((sniff)). May I be peaceful ((sniff)). May I live with ease.’ And I just kept repeating that to myself. And err... that got me through.”

This mantra, often introduced in week four as a kindness practice on the course, is derived from the Buddhist Metta bhavana, or loving-kindness meditation, and can be deeply affecting, as it acknowledges vulnerability and is designed to help individuals confront difficulty with kindness, attending mindfully to present-moment experiences. In the remembering, Tanya leaves out of the mantra, deliberately or not, the third line; “may I be healthy.” However, she is keen to stress how important discovering the mantra and mindfulness were, in helping her face difficult challenges like surgery. They also help adjust her understanding of living with the uncertainty of palliative care:

“Its meaning is ambiguous, in that it doesn’t mean certain death, but I don’t know…I don’t know what the future holds. And I’ve been living with uncertainty since I had the surgery. And … I felt, well, I got through the surgery, I healed very well.”

After surgery, Tanya came home, and the UK went into lockdown. Rather than catastrophising about the future and the possibility of cancelled treatment, her “mindfulness practice has come through in gardening.” Although she still feels uncertain, she is focused on the here and now and finding joy in everyday activities. The existential threat of death, while still present, is held somewhat in abeyance, as she finds meaning and pleasure in what matters to her. Tanya was offered an opportunity to stop the recording when she became upset, however she was keen to continue talking about how mindfulness has worked for her in a practical way, giving her the “ability to do something now, that I couldn’t do before” and this, perhaps, was an obvious example of her recognising and staying with an uncomfortable feeling. Whenever she feels under threat, “I will just keep doing what I’m doing, and eat healthily, try and be relaxed, do things I enjoy.” Not only is she reflecting on her self-kindness around the surgery, but Tanya is also showing compassion to herself in the interview, by remembering and sharing the activities and events that give her pleasure and allowing herself a mixture of emotions as she does so.

Putting mindfulness to the test in an emergency is something that also worked for Jan, who is recovering from surgery. She describes a recent situation in hospital, where she was feeling stressed and accessed some short meditations that she had downloaded to her phone: “I used a mindful waiting one, that just kept playing over and over...so they really helped, actually.” Jan believes this mindful waiting meditation helps her become “calmer” and manage her anxiety about going to hospital and says she plays it “over and over” which suggests that perhaps it is used as a necessary distraction, rather than in a more flexible, attentional way. Henry also uses short meditative practices, usually when he experiences relationship difficulties:

“There have been a small number of occasions where in a sense, I’ve got up and walked away from the conflict zone and tried to get into that short meditation. It’s only something like a three-minute meditation. But I think … I’m probably better placed to sort of disengage and cry and go back and look after myself in my cave, or whatever.”

Meditation is seen as a short, sharp break; a pause to help retreat from the “conflict zone” and refocus on the self. Again, Henry, like other participants, use mindfulness to “disengage” or “distract”, however once again it is unclear whether the practices are seen as deliberately diverting attention away from unwanted thoughts and feelings to escape or avoid them, or whether they provide a space to allow for a more flexible engagement with them. Henry describes having a cry before returning to look after himself, which suggests it is the latter, as he pays attention to and allows for his difficult feelings.

Interviews were conducted at the beginning of the first coronavirus lockdown between March and May 2020 and all participants talked about how the skills learned in the mindfulness course, helped them manage it. For Jan: “it’s not been monotonous or boring, which it could’ve been before. It’s helped …cause my mind’s calmer, more organized.” For Henry, being isolated means: “I’m better able to put the positivity in context… I spend far more time on the phone to members of the church communities, just keeping in touch with them, and maybe the kindness thing, through mindfulness, is part of what is driving those conversations.” Sam thinks that if she hadn’t the course before lockdown, she would have been “stressed” and unable to concentrate: “I would be climbing the walls. And I don’t find that. I find that I’m able to give that compassion to myself to do the things that I want to do and deal with it.”

Mindfulness skills helped participants deal with challenges as the pandemic took hold, and all recognize and appreciate the timeliness of having finished the course just as the UK went into lockdown. Many of those living with cancer had operations and procedures cancelled or were unable to go to hospital for check-ups, however, rather than ruminating about it, Maya is one among many who says:

“I feel at peace with the whole … situation. I’ve got to have further surgery. So that’s been put off cause of the …lockdown. But, um, but I think that will be a good thing. I think I’ll be stronger physically and mentally then when I do have the operation.”

Maya has reframed what might have been upsetting or stressful and now sees lockdown as a “good thing” because it gives her time to prepare for surgery. Henry talks about the “positivity” of lockdown, as it gave him time to concentrate on more mindful activities. However, Lucy’s interview took place when some restrictions began easing and initially, she describes feeling unsettled:

“I’ve been very sort of ((gulps)) … disturbed this week because … everything’s changing on me and I’m not coping very well. Or I wasn’t. But yeah … I done the breathing and I sort of sat back and paused and looked at it and thought, ‘ok, why are you worrying?’ … whereas before I’d let the worry take over, but this time I don’t. I seem to be more erm, open to it, more friendly to other people, because we’re all in the same situation … we’re all thinking the same sorts of things.”

Lucy brings together many of the themes explored here; she notices her difficult thoughts and feelings, uses the breathing skills she learnt through mindfulness to create a space to acknowledge and reflect, and puts a pause on her ruminative thinking; questioning where it is taking her and the evidence behind it. She also refuses to let the worry and catastrophising take over, in part because she has a shared humanity and can see others suffering, which makes hers easier to bear and this means she can also be compassionate to others and herself. She also views uncertainty differently, saying; “Uncertainty is part of life. Uncertainty is what happens. You can’t control everything…. it’s not what’s happening to you. It’s how you react to it that matters.”

Uncertainty is ubiquitous, part of life and experienced by everyone, and Lucy recognizes that it’s the reaction to it, not uncertainty itself, which determines her positive or negative emotions. Many participants, including Barbara, agree that mindfulness has helped bring a different perspective to lockdown:

“If I hadn’t had the mindfulness, it would have been ((gasp)) ‘got to find myself things to do!’ And I’d have been going round doing the housework for ever … and this circular...eurgh! and I’m so worn out, I fall asleep. But this time I am sitting in my front room with my dog in the room. And I’m happy. Do you know what I mean? I’m content.”

3.3.7.3. Subtheme 3: The ephemeral: “my one wild and precious life.”

Part of being able to deal with ruminative thinking means focusing on the ‘here and now’, which many participants mention. Tanya, who hasn’t had a scan or blood test in three months, says; “I’m dealing with it, because I’m thinking in the moment and because I’m thinking of the now and because there’s nothing I can do about it.”

The recognition that rumination won’t change her situation allows Tanya to let go of the worry of uncertainty and return to the present. However, this can, as Henry and Barbara suggest, take some “discipline” and there is a fear among some participants, like Anna, that the balance and benefits they were able to achieve through mindfulness might be lost, if they don’t keep the practices up:

“It’s very easy as you move further away from the sort of trauma of the diagnosis and the treatment … to slip back into old patterns? But I worry for the future because ...there’s that narrative again! … I feel that I need to just gently go over everything um and just see where I’m at now, however many months on. Um, and... before I would never be able to look to the future, and I’d got up to being able to look to three months, but maybe now I can look to six months… hopefully.... ((laughs)).”

Tanya notices some concerns about losing the urgency of doing mindfulness exercises as she gets further away from the trauma, yet also reflects where her thoughts are taking her in this “narrative” and pulls herself back, laughing at the familiarity of the script. Once again, the mechanisms of mindfulness show themselves in this recognition of her difficult thoughts towards her life expectancy. She also uses the word “gently” to describe how she will attend to the mindfulness coursework, as if to give it less weight and perhaps distance it from the judgement she might normally use. When she allows herself to think of the future, although she looks beyond the short-term, she holds it tentatively. Maya also believes she needs to remind herself of her practices when things get difficult:

"That positive part of you … I'd lost it. And then gradually through the mindfulness that, you know, it was like, um, going from light to dark, dark to light. It was that shift. And now when it starts going a little bit dark, I've got those tools to go 'right!' … You know, if I catch it … I say 'go and do your mindfulness' … I just feel more alive and brighter."

"Catching" the thought before it takes Maya to a "dark" place allows her to use the tools she has learned, although it means she has to "go through that whole acceptance thing again, so that's a bit tricky sometimes. And I can… have that negative voice, if I don't, erm, stop it, and do me meditation. That's really helpful … because otherwise it can quite easily go down."

Participants like Maya see mindfulness meditation as an active and constant checking process, of being aware of rumination and then going to the practices to get back to a more balanced state of mind. Support from Maya's husband, who also notices her negative thoughts, reminds her of the benefits that practise can bring and part of this is knowing that difficult thoughts and feelings are temporary. Many participants come back to this idea, like Lucy:

"Everything is ephemeral, everything is thoughts, emotions, all that stuff… there is a part of you that is stable. But … you've got to get rid of all the, umm, stuff around it first. If I start having a go… I think, this will pass, this is just momentary. It'll pass."

Lucy knows the difficult thoughts and feelings and the judgment that accompanies them, are temporary, rather than being permanently fused within her. The "stable" part is the essence of her that she wants to connect with, not the "stuff around it", which is perhaps the negativity and ruminative thinking. Anna says this core idea of mindfulness, of knowing difficult thoughts and feelings are impermanent, is hugely comforting:

"There's a kind of a safety net there, that I could go back to breathing and just... I can't do anything about this now, I know what the problems are. And it will pass and it’s having that confidence that it will pass. And so, I think that yes, probably, it also gave me that, it’s …like a sort of safety blankey.”

Even though Anna feels the warmth and safety of mindfulness, she knows that with her tendency to judge, as with other participants with a harsh, self-critical voice, there is sometimes an expectation she should be doing mindfulness differently, or more often, and here too, she brings in the idea of acceptance, impermanence and holding the practice more lightly:

“Just accept that I’ve been a bit judgmental … but it’s not the end of the world … tomorrow is another day. I think it is a work in progress. But then life is a work in progress. And I think that we go along expecting things…. and … it sounds a bit corny… we’re not looking at the journey. We’re just so focused on achieving. But actually, one should just be enjoying every day.”

It is not about control or achieving for Anna, but rather acknowledging that growth and recovery depends on accepting the impermanence of negative thoughts and feelings and letting them go. For Tanya, the ephemeral nature of life is perhaps heightened because she is in palliative care and the time she has left is limited, suggesting there is little point in tying herself to expectations of what might happen: “Who knows what the future holds because we don’t know, do we? So, we just live in the now and we enjoy these flowers in the garden and we enjoy the sunshine.”

The last word goes to Henry, another participant with incurable cancer, who echoes this philosophy with the words of Mary Oliver, whose poetry is often used on the course:

“I can’t remember what the final sentence is, but I tend to paraphrase it anyway; ‘what am I going to do with what is left of my one and only precious life?’ …. I tend to add in, ‘my one wild and precious life’ …. I think what Mary Oliver was saying to me at the end of that poem, is something about positivity. And don’t waste the time that you’ve got in front of you. Use it to good effect.”

Chapter Four: Discussion

4.1 Summary of study findings

Mindfulness is summarised by Jon Kabat-Zinn as “the awareness that arises from paying attention, on purpose, in the present moment and non-judgementally” (Kabat-Zinn, 2003 p. 145). In this study, participants reported they had learned to cultivate this awareness, were trying to live in the ‘here and now’ and aimed to bring a curiosity and kindness to thoughts, feelings, and sensations as they arose, even if they were painful. In this discussion, I examine how using a sequential, explanatory mixed methods approach helped investigate how individuals developed a greater understanding of their reactions to cancer, to rumination and to fears of compassion after a mindfulness course, and what meaning they attached to any changes. I explore the relevance of this research to the field of Counselling Psychology and to supportive cancer care and discuss how it might contribute to existing research and inform future work. Finally, I consider my own part in this study as a researcher with a cancer experience, who has been working with patients in active treatment both in the NHS and the third sector.

While the quantitative findings suggest a statistically significant positive shift in negative adjustment to cancer, to brooding and depressive rumination and to fears of compassion towards the self; the qualitative element allowed for an examination of how participants acknowledged and allowed for this shift, which revealed a more complex process than statistical analysis of the quantitative data might suggest.

Individuals came to mindfulness with different cancer experiences but were struggling with similar things; the existential fear of death, the reality of cancer recurrence, the desire to be seen as ‘strong’, not ‘weak’, the resistance to compassion, and the blocking of physical and psychological pain to prove to themselves and to others that they were ‘fine.’ For many, holding this together created feelings of overload and overwhelm. There was an initial expectation that mindfulness might eradicate these difficulties, and some surprise when the practice appeared more challenging than expected, but by approaching suffering with curiosity and by cultivating acceptance and self-kindness, participants reported being more able to choose how they reacted to their thoughts and feelings, to their disease and to their place in the world.

4.2 Outline of Insights Gained from Quantitative Analysis

One of the main aims of this part of the study was to examine whether there was a shift in individuals’ mental adjustment to cancer, rumination, and fears of compassion in those with cancer after a mindfulness-based group intervention in a community setting. There was a statistically significant decrease in participants’ levels of negative coping (anxious preoccupation, avoidance, fatalism, and helpless/hopelessness), a reduction in their depressive and brooding rumination and a lowering of their fears of compassion towards themselves after the mindfulness course, regardless of the severity of the disease or time since diagnosis.

This answers the research question, by supporting the initial hypotheses that there would be a shift in these concepts after the intervention, and a direct and significant correlation between them. It also adds to research suggesting similar changes in those with breast cancer after an MBI tailored to a cancer population (Hoffman et al., 2012a) and it extends the literature by examining change within a mixed cancer cohort. In addition, it also interrogates that change on an individual level, by using the Reliable Change Index, which suggests most participants reported meaningful and clinically significant change, on at least one or more measure, which is unlikely to have occurred by chance.

4.2.1 Negative and positive coping

The findings suggest that, as a group, most participants (*n* = 19) reported a new sense of acceptance and agency over how they perceived their cancer, with a greater awareness of unhelpful behaviour and a perceived growth in their ability to cope, as measured by the Mental Adjustment to Cancer Scale (MACS). However, it is important to note that a significant decline in negative reactions to cancer does not necessarily lead to an associated growth in positivity. While most individuals (*n* = 13) did report a more positive state of mind and adaptive coping strategies after the intervention, this was not statistically significant. Looking at the reliable change within each individual, six saw a clinically meaningful decrease in their negative coping but only two reported a statistically significant increase in their positive reactions to cancer.

It may be that participants were not experiencing a positive change in their feelings towards their cancer, however an alternative explanation may lie in some of the statements in the subscale suggested as demonstrating ‘positive’ coping, such as ‘I try to fight the illness’, ‘I firmly believe that I will get better’ and ‘I see the illness as a challenge.’ These may conflict with some aspects of mindfulness, and for some, the cancer experience itself. Six of the participants had cancer at stage 3 or 4, where it has spread to the surrounding tissues or other parts of the body, and at least three were in palliative care. Some of the ‘positive’ statements might not be viewed as such for those whose prognosis suggests they will not get ‘better’, or who do not see their illness as a ‘challenge’ or choose to ‘fight’ it. Mindfulness encourages individuals to lean into difficult thoughts and emotions with acceptance and awareness, rather than ‘fight’ them and this may also have influenced responses.

A further ‘positive’ statement is ‘I have put myself in the hands of God’. While spiritualism can be viewed as an adaptive coping strategy for some with cancer (Büssing et al., 2007), the word ‘God’ suggests a monotheism which fits religions such as Christianity, Islam, and Judaism, but might not resonate with those who are not religious or whose belief system lies elsewhere. Mindfulness also has its roots in Buddhism, which does not acknowledge a supreme god or deity.

Another statement considered ‘positive’ is ‘I keep quite busy so I don’t have time to think about it’ which might be considered an avoidant or suppressive, rather than an adaptive coping strategy and the qualitative findings appear to support this. One of the ‘negative’ coping statements was ‘at the moment, I take one day at a time’, however participants in the qualitative part of the study perceived the idea of living in the ‘here and now’ as a *positive* coping skill learned from the mindfulness intervention.

These apparent contradictions make for a richer and more complex study and is one of the benefits of a mixed methods approach, however future researchers using the Mental Adjustment to Cancer Scale in a mindfulness intervention may wish to consider how best to do so, if they are relying on quantitative analysis alone, as individual differences in the conceptualization of positive and negative reactions to cancer may be harder to explore. There is also some scope to examine whether any adjustment is related to an enduring state or trait, or a response to another life event, unconnected with cancer.

4.2.2 Ruminating and reflecting

The focus of mindfulness on the present moment is thought to help counteract negative or sad feelings which are often characterised by depressive or brooding rumination, considered a maladaptive way of dealing with suffering. As a group, most participants in this study saw their depressive (n = 15) and brooding (n = 15) rumination decrease between T1 and T2, a finding which corresponds with existing research suggesting that more mindful individuals tend to be less depressed (Svendsen et al., 2016). Depressive rumination saw the greatest intra-individual change too, with seven participants reporting a reliable improvement in scores.

With reflective rumination, which is thought to be more adaptive, the group scores were mixed, with some participants reporting a fall in scores (*n* = 8), some a rise (*n* = 9) and some, no change (*n* = 5). This may be because mindfulness encourages a degree of reflective introspection by turning towards painful thoughts and feelings which some may have found challenging, and this, again, appears to be supported by the qualitative analysis in this study and by research in those with breast cancer (Pössel & Pittard, 2019). Intra-individually, three participants saw their reflective rumination scores fall and only one reported a reliable increase.

The positive correlation between reflection with brooding and depressive rumination, present in T2 but not in T1, also suggests that reflection may have contributed to some negative affect, at least in the short-term, which is consistent with existing research in those with breast cancer (Brown et al., 2019). While reflection can lead to productive insights into adversity, it can also be associated with depressive thinking (Miranda & Nolen-Hoeksema, 2007) as it can draw individuals into negative ways of thinking and adversely affect mood.

Some studies suggest the mechanisms of mindfulness, with its emphasis on mindful attention (observing), emotional regulation (decentring, accepting) and meditation, may have negative effects (Britton, 2019). One randomised controlled trial (RCT) of mindfulness versus relaxation training for those undergoing chemotherapy, suggested the mindfulness intervention was associated with increased social avoidance, symptom distress and a reduction in the quality of life, with the authors cautioning against using MBIs during the acute stage of illness (Reynolds et al., 2017).

However, this study examined a brief mindfulness course of three sessions, which was a modified version of the MBCT-Ca (Bartley, 2012). While symptom related distress may not be addressed by some mindfulness interventions, the major strength of the eight-week MBCT-Ca programme is its combination of group and home exercises, with a gradual exposure to body scans, meditations, and the cognitive model of cancer distress, where experiences are deconstructed within a group dynamic, with a focus on developing kindness and compassion. A recent systematic review of mindfulness-based interventions in cancer suggested larger, positive effects in those interventions which followed a strict adherence to protocol (Cillessen et al., 2019) which the MBCT-Ca intervention investigated in this research, follows.

It is also worth considering whether the statements in the Ruminative Responses Scale (RRS), said to represent adaptive reflection, are consistent with mindfulness training. Four of the five statements categorised as ‘reflective’ are analytical (‘analyse recent events to try to understand why you are depressed’, ‘analyse your personality to try to understand why you are depressed’, ‘go someplace alone to think about your feelings’, ‘go away by yourself and think about why you feel this way’). While mindfulness encourages the individual to acknowledge suffering, it might be argued that some of these statements suggest a more interrogatory response to low mood, which may provoke negative reaction or self-judgement.

The timing of the post-course surveys should also be noted. Most of the participants finished their courses at the end of February and the beginning of March 2020, as coronavirus cases began rising and the UK headed into lockdown. Some participants had just finished active treatment, but others were still receiving medical care and may have been reflecting on how this would affect them, provoking further challenging thoughts and feelings. Post-course, the individuals’ plans may have been disrupted, treatment affected, and isolation increased, and this was explored in more detail in the qualitative findings.

4.2.3 Fearing compassion

In this part of the study, reflection was also positively correlated with fears of compassion towards the self and for others after the mindfulness course. This fits with research suggesting that rumination can be linked to a fear of, and in some cases, an active resistance to, affiliative emotions such as kindness (Gilbert, 2015). It was notable that in both T1 and T2, those who expressed fear of compassion for the self, also reported a fear of compassion to others, and from others, suggesting that some sought to avoid kindness, or found it threatening. Although there was a decrease for most participants in their fear of showing compassion towards themselves between T1 and T2 (n = 15), the number of those seeing fear of compassion for others and from others fall, was smaller (n = 12) and not significant.

There is a large measure of variability in the fear of compassion scales that was not present in the other measures. For example, in fears of self-compassion, some (n = 10) participants reported scores of below 10 in the pre-intervention questionnaire, whereas others (n = 5) began the course with scores above 30. Although the difference in pre- and post- scores for the fear of compassion for others and from others showed a normal distribution, this subscale showed significant levels of skew and kurtosis, post-intervention. This is a small sample (N = 22) and therefore a degree of skew and kurtosis may be expected, however on further analysis, this effect appears to have been magnified by one outlier, a participant whose fear of self-compassion score rose from 38 to 65. While excluding this outlier may have ‘strengthened’ the findings, or produced less variability, doing so would have felt wrong, ethically. Just as each participant experiences their cancer differently, so they will react to the mindfulness course in different ways too. Honouring divergence and contradictions felt important and indeed, is suggested by studies urging a more balanced approach to reporting mindfulness interventions by supplementing data with individual change, whether improvement or deterioration and by using qualitative experiences, to help analyse the impact of any outliers (Britton, 2019).

4.2.4 Being self-critical

A note here on self-criticism, which emerged as a strong subtheme in the qualitative analysis. Those who scored highly on self-critical statements, drawn from the brooding rumination and fears of self-compassion subscales, reported a fall in these scores after the mindfulness intervention. Research suggests rumination and self-criticism is associated with an over-identification of thoughts and the activation of the threat system, increasing the possibility of psychopathology (Brown et al., 2019; Gilbert, 2017; Pinto-Gouveia et al., 2013). Fears of compassion, especially accepting it from others and showing it to the self, is associated with self-criticism and depression in student and patient samples (Gilbert et al., 2011) and a sense of shame can increase levels of harsh, self-critical thinking, preventing self-kindness (Gilbert & Irons, 2005). One way of developing a less judgmental, and more soothing, self-compassionate approach is by mentalising the self-critic (Gilbert, 2015) and noticing unhelpful ways of managing distress and emotional dysregulation. However, individuals can be fearful of this, blocking or resisting compassion, which is especially common in those who have experienced trauma (Lawrence & Lee, 2013). Research in women with breast cancer also suggests that individuals with an insecure attachment style, who may have experienced an unpredictable and unsupportive environment, can find it difficult to access self-compassion, and are more easily able to engage in self-criticism (Arambasic et al., 2019).

Self-criticism was not a prime focus of this study, however, there was a strong positive relationship between this and fears of accepting kindness *from* others or showing it *to* them, which reflects studies suggesting high self-critics may actively resist self-compassion (Neff & Vonk, 2009). A judgmental approach is strongly associated with aspects of internal shame, or viewing oneself as inferior, inadequate, or flawed (Gilbert & Andrews, 1998). Shame can also enhance self-criticism (Castilho et al., 2013) and both are negatively associated with self-compassion. Being non-judgemental is a protective factor against shame and self-criticism, and self-compassion allows for the emotional regulation of these emotions through self-soothing, stimulating the parasympathetic, or resting system (Germer & Siegal, 2012; Neff, 2016).

The findings that those who were self-critical also struggled to accept kindness, fits with Neff's (2003) theory of self-compassion with its six facets: three positive ones including self-kindness, seeing personal failures and weakness as part of a common humanity, and accepting the present without judging and three negatives; being self-judgemental, feeling isolated or lonely, and overidentifying with difficult thoughts or feelings. These negative facets and their relationship with fears of compassion are explored in more detail in the qualitative part of the study, but practitioners may need to be aware that a self-critical voice can drive negative thinking in how individuals believe they are coping with cancer and may influence how they judge their mindfulness practice itself. In a cancer setting, there can be guilt about not staying 'positive' (Periyakoil, 2008), illness-related shame (Trindade et al., 2018) and/or a need to show 'survivorship' (Kaiser, 2008).

4.2.5 Implications and limitations in quantitative analysis

On a group level, most participants saw a statistically significant decrease in their negative reactions to cancer, depressing and brooding rumination and fears of compassion to the self, and intra-individually, these measures showed the most reliable improvement too. However, this did not mean negative thoughts or emotions were not present during or after the mindfulness intervention. Indeed, some individuals saw a rise in depressive and/or brooding rumination and negative coping, and although only one of these is considered a statistically significant change when using the RCI, the implications for practitioners might be that in assessing for suitability, participants should be asked about their expectations of mindfulness, be fully briefed about the protocol of the course and what to expect, and to be supported by qualified and experienced mindfulness teachers throughout, if adverse effects are experienced. Research into potential adverse effects in mindfulness studies suggests some challenges and potential side-effects (Lomas et al., 2015), however as mentioned earlier, studies are limited and the greatest risk may be in poor teaching and lack of understanding in mindfulness interventions, rather than mindfulness per se (Van Gordon et al., 2017). This researcher adds to those calling for clinicians to recommend mindfulness teachers with sufficient experience and training, and for researchers in various mindfulness techniques to report positive, negative, null, and contradictory findings in order not to overstate the value of the interventions (Britton, 2019).

This study focused on the pre- and post-mindfulness intervention scores and is consistent with research suggesting enhanced acceptance, rather than avoidance or suppression, of emotional states and a reduction in some, but not all, of participants’ distressing feelings of brooding and depressive rumination, together with an improvement in coping mechanisms (Henderson et al., 2011). Henderson et al.'s study into breast cancer participants suggests such effects may be short-term, however others report decreases in distress and rumination up to nine months after the intervention (Cillessen et al., 2018). As this is not a longitudinal study, it is not known whether these effects would sustain beyond the post-intervention period and longer-term research examining whether mindfulness practice is adhered to and effects maintained, would be beneficial in a mixed cancer population.

Some questions were raised during this part of the study which may also benefit from further research. It remains unclear, for example, if individuals who seek out a mindfulness course are more open to help-directed action and expect positive changes in emotional affect and compassion. It is also not known whether participants were embarking on additional forms of health behaviour unconnected to the intervention, such as exercise, diet, and other forms of relaxation and rest, and this may be explored further using the Health Behaviour Scale for Cancer Patients (HBSCP), a new measure for those with cancer (Cecon et al., 2021).

There are limitations to this part of the study, as it is self-report with a self-selected cohort, and this may limit its findings. Also, participants might have experienced a shift in their disease trajectory, or other life events unrelated to mindfulness, which affected their results but of which I was not aware. Of the initial 31 participants who successfully filled out the pre-course questionnaire, six failed to complete because the course was cancelled due to coronavirus or they were ill, but three did not give a reason. The dropout rate is still lower than many studies into mindfulness in those with cancer which suggest dropout rates of around a third or more (Labelle et al., 2014; Schellekens et al., 2016). This may be because centres either ran an introductory session or fully briefed individuals to assess suitability and describe how the course worked before sign-up. Research suggests mindfulness interventions adhering to original protocols showed larger effects than those which had been adapted (Cillessen et al., 2019) and it may be that following the clear MBCT-Ca protocol and informing individuals of what to expect, helps with both adherence and outcomes.

Perhaps the strongest limitation is the small sample size and lack of control group which may diminish the strength of the findings. Also, despite seeking diversity by encouraging all UK Maggie’s centres to take part, participants were predominantly female, middle-aged, white, with high levels of educational status, which reduces the generalizability of the study to other ethnic, socioeconomic and gender groupings. Although this seems typical of many mindfulness-based intervention studies (Chin et al., 2019; Tacón et al., 2004), this study adds to those calling for a further exploration of potential barriers to MBIs and whether engagement might be increased using flexible means of delivery, such as web-based designs (Archer et al., 2020).

4.2.6 Summary of quantitative findings

A new and important finding in the quantitative part of the study, which may help inform clinical practice and policymaking in cancer and compassion, is the suggestion that a disease-specific mindfulness course can help shift negative coping, rumination, and fears of self-compassion both on a group level, and on an individual level too. Participants reported being more able to cope, had fewer depressive, or brooding ruminative thoughts and felt a greater sense of self-kindness. However, the strong positive relationship between reflective rumination and all fears of compassion subscales after the course suggests reflection can, at least in the short-term, provoke challenging feelings around kindness.

Another strength of the study is the strong association between fears of compassion to others, from others and towards the self and the relationship between compassion and self-criticism; understanding this may help practitioners developing interventions for those with cancer. A further strength is using participants who took part in a mindfulness-based intervention based in a community cancer support setting, rather than in a hospital-based environment. The qualitative part of the study suggests this helped develop the trust and safety needed to make mindfulness ‘land’, and this might have influenced how they responded both to the quantitative survey and the qualitative interviews, too.

4.3 Outline of Insights Gained from Qualitative Analysis

While the research hypothesis was supported; there was indeed a change in negative coping, rumination, and fears of self-compassion after the mindfulness intervention and a relationship between these factors; the qualitative analysis examined patterns of experience, behaviour, mechanisms, and processes in the shifts in ruminative thinking, attitudes to cancer and ability to hold self-compassion, adding a richness and complexity to the study.

One of the main insights from the qualitative analysis is that mindfulness has huge potential for those with cancer, but it is not a cure-all. Many of those who came to the intervention had an urgency or desperation driven by depressive and/or brooding ruminative thinking, had tried other coping strategies but found them wanting and thought mindfulness might give them some respite and relaxation tools. However, while they were motivated to try it, there was initially some uncertainty about what it entailed; most believed it had a spiritual element to it, some were sceptical, and there was a hesitancy too, about the prospect of disclosing painful experiences in front of others. What individuals discovered was an immersive intervention that was perhaps more challenging and involved more work, than they anticipated.

While most saw positive changes in rumination and negative coping, mindfulness had taken many to places which could feel frightening and some contemplated giving up. The trust felt in the teacher, the setting and the group was crucial in helping them face difficulties that they had previously avoided or suppressed. The manualised nature and protocol of the MBCT-Ca course took them through the cognitive processes involved in both cancer and mindfulness, normalised reactions and allowed participants to notice and accept them with kindness and compassion. Most began the course not wanting to reveal much about themselves, however by the end, they were eulogising about the benefits of sharing within a group. This idea of sharing coping fits with existing research into mindfulness' group benefits of common humanity, attachment and compassion which can help with positive, affective change (Cohen & Janicki-Deverts, 2009).

Those who began with a strong self-critical voice recognized its origins and still had it by the end, but were kinder about it, even while accepting the limitations of mindfulness to eradicate self-judgement completely. While mindfulness meditation was not always being practiced daily, the mindful way of being was utilised in other, meaningful, everyday activities such as painting and gardening and in emergencies, including before surgery and during coronavirus, as the UK headed into lockdown. However, there was, for some, a fear of losing this new skill. Those whose life was about achievement, success, and motivation, who had what Gilbert (2010) would describe as a high threat/drive system, and were goal-driven and future-focused, initially applied the same tactics to mindfulness, running the risk, as Jan said, of “over-efforting” and bringing the very same judgmental voice they were trying to quieten, to the discipline of mindfulness itself.

Participants were, in the main, feeling more “positive” about their life with cancer, catastrophising and ruminating less and feeling, as Emma said, “much kinder” to themselves. The key processes which allowed for this, and which emerged from the qualitative analysis, were noticing and allowing for pain and suffering, seeing it part of a common humanity, and integrating kindness into life with and beyond cancer, all while acknowledging there were inevitably, going to be stumbles along the way. This compassion-turned-inward and awareness of the universality of suffering, builds on Neff’s research into self-compassion. It suggests mindfulness interventions can cultivate an acceptance of ‘what is’, rather than what is to be got ‘rid of’; moving towards ‘being’ rather than ‘doing’ (Segal et al., 2002), and for these participants, this seemed to mean accepting the truth of the illness, while letting go of the cognitive overload, emotional overwhelm and exhaustion of maintaining the appearance of coping.

4.3.1 Contradictions in compassion

Individuals believed a more non-judgemental approach had encouraged self-compassion, which helped nurture compassion to others and allowed for an acceptance of kindness from others, however this did not always appear to be reflected in the earlier, quantitative analysis. Henry said, “if you can’t be kind to yourself, you can’t be kind to anyone else”, Lucy reflected that “it made me happy to see others happy”, Anna believed kindness was a “reciprocal arrangement” and she was now more able to accept it, because she could show it to herself. Individuals suggested kindness fed on and perpetuated itself during and after the mindfulness intervention, like a virtuous circle.

However, although most participants in the qualitative stage saw their fears of compassion decline, the Reliable Change Index suggests only two out of ten showed a clinically meaningful decrease in their fears of expressing compassion for others, and three out of ten, in their fears of responding to the expression of compassion from others and towards the self, suggesting that perhaps the shift was not as dramatic as most had perceived or reported. This might be because some individuals wanted to be seen as being more compassionate than they felt, but is perhaps more likely, that they were struggling with side effects such as fatigue, were still on medication or had recently finished active treatment, and while they were able to acknowledge their suffering and the judgment and expectations attached to it, developing compassion was perhaps a slower and more complex process.

4.3.2 The cultural context of ‘fighting’ cancer

Many participants indicated that much of the negative and ruminative thinking was driven by the need to prove they were ‘fine’ and to reclaim their identity of being healthy by being busy, and this can be seen in the wider sociocultural context of cancer, where those with cancer are in a ‘war’ and expected to ‘fight’, military metaphors which are often used in UK cancer care (Semino et al., 2018) and this talk of a ‘fighting spirit’ in cancer may engender a feeling of guilt among those living with it (Watson et al., 1999).

The battle metaphors were used by some participants to describe being at war with their thoughts and feelings around living with cancer. Lucy says she was in her “own little battle” to try to not to get sucked into ruminative thinking. Barbara was busy “fighting” her body when it tells her its hurting. Cancer and the thoughts and feelings around it, provoked a “fight, flight, freeze” response for Emma, Anna talked of a “bitter struggle” with her disease. Mindfulness brings an awareness of the stress response created around this ‘fight’, and suggests leaning into discomfort, but as previously discussed, it is not easy, especially when the cultural discourse and social context of cancer seems driven by the need for individuals to tackle this disease and ‘win’. The ‘failure’ to do so, or to meet the expectations of the self and others in getting back to ‘normal’ was raised by many participants, and mindfulness had helped them become more aware of how the guilt, shame and blame attached to this this, had affected their emotional recovery.

4.3.3 The “gift” of allowing for uncertainty

Mindfulness does not get rid of pain, but it did help these participants turn towards and observe it. It does not get rid of the struggle with identity and perceived loss of self, but the recognition of this can help individuals feel kinder to themselves. It does not remove uncertainty, but it does allow for an understanding that uncertainty is part of life and shared by all. It has given these participants strategies; it is “a gift”, “an anchor” or “another tool in the toolbox”; participants felt there had been a “load lightened”, a “door opened”, a “lightbulb moment”, a “mind shift.” Talking to others was like “a flower opening”, “empowering, brilliant”, being part of “a gang” and on the “same team”, with “people who get where you are.” Self-compassion meant letting go of being perfect, or being perpetually busy, and accepting fragility; it was a “broken plate”, a “wrong note”, an “ugly teddy” or a “soft stone, warm in your hand.” Compassion to others was baking the “first apple pie”; accepting it was allowing someone to buy you a gift like a handbag. For these participants, it was about being deserving, knowing they were important and of value and being able to relinquish some responsibilities and expectations, while also recognising small, but meaningful, achievements.

4.3.4 Gains and losses

The word used most frequently by participants to describe themselves post-mindfulness, was “calmer” but they also described being “more clear-headed”, “slower”, “more thoughtful”, “more connected”, “more honest”, “more alive and brighter”, “at peace, content”, “more accepting of uncertainty” and “more reflective.” It is interesting that individuals mainly described what they were “more of”, rather than “less of” after the intervention, embracing a “what is”, rather than a “getting rid of.” They came to mindfulness to lose something, usually to feel “less stressed, depressed and irritable”, yet ended up gaining, becoming “the real me”, “putting all the little bits back”, finally “using my genuine smile” and “the part of my brain that had gone to sleep.” Some recognized that one mindfulness course could not shift their self-critical voice, but it had allowed them to understand it. Others asked themselves whether it was the intervention or the cancer itself which allowed them to feel worthy of time to themselves, and to be loved by others.

The process of the interview reminded many of the value of mindfulness to them, and for some, there was a feeling of loss now that the course had ended, and the group dispersed. Perhaps it reminded those post-treatment of the feeling of being held and then left by the medical team, or maybe, as the interviews took place in lockdown, they were now in isolation and missing the dynamics of the group, or the discipline of regulated, weekly self-care.

All those interviewed recommended a mindfulness-based intervention for individuals with cancer who are struggling with challenging thoughts and feelings. Barbara believes mindfulness is one of the tools that can help equip individuals to deal with life beyond the disease and insists she would tell others with cancer that: “you must, must do for yourself. Not you might. You must. Because if you don’t do it, you end up like I did." However, she also issues a note of caution about the readiness of individuals in moving towards the acceptance of difficulty: "What's the situation that people are in? Have they really got the time to acknowledge it anyway? Would they acknowledge it?" Lucy says individuals "have to be ready" and that straight after diagnosis might not be the right time because it is a "shock to the system" and there's "too much stuff going on" and the appropriate timeliness of mindfulness is worth considering both for clinicians and individuals alike and merits further research.

4.3.5 Implications and limitations

The qualitative part of this study examined processes and mechanisms in mindfulness that participants believed enabled a change in negative coping, rumination, and self-compassion, and this has implications for those with cancer thinking of embarking on a course, as well as practitioners, cancer support services, and Counselling Psychology as a profession.

Individuals must have the motivation to do the course and have trust in the teacher and setting, however timing and choice are also important. These participants chose the course because it was the right time, space, and place for them and although many had finished active treatment, some were still on hormone therapy, were recovering from surgery, or receiving palliative care. Practitioners should check how medication such as hormonal treatment, or persistent side effects, may hamper participation.

Many participants began the course with ruminative thinking, self-criticism and for some, a degree of shame about how they were coping with side effects or difficult thoughts and feelings. Practitioners could help participants understand and normalise these physical and psychological challenges that often exist post-treatment, and Counselling Psychology also has a broader role in tackling the stigma felt by those with the disease by helping to challenge and change the narrative around cancer survivorship. More people are living with and beyond cancer than ever before (Cancer Research UK, 2021) however self-criticism and self-blame can result in identity threat and associated psychological distress in those with the disease (Knapp, et al., 2014). Paying attention to the potentially stigmatizing effects of a cultural discourse that focuses on ‘fighting’ and being aware of societal and familial expectations in relation to cancer and its treatment, could help participants be more accepting of their reactions to living with and beyond cancer. This MBCT-Ca course has appropriate language and refers to the cognitive challenges around the disease and this would help when designing other psychosocial interventions for those with cancer.

Further research could investigate behavioural and characterological self-blame in the context of cancer and how this might influence responses to a mindfulness intervention, which encourages a turning inwards to face such difficulties. Interventions that encourage individuals to feel truly seen and heard and where “kind words can open the door of our hearts” can cause “old wounds to resurface” and bring intense pain, with the potential for “backdraft” (Germer & Neff, 2019 p. 5). Backdraft happens when a firefighter opens a door and the blaze behind it, rushes in to overwhelm them. This seemed to happen with many of the participants in the weeks when they were asked to lean towards painful memories, thoughts, sensations, and feelings. For those individuals with a particularly complex developmental history, involving some trauma or neglect, observing one’s suffering, and moving towards compassion can be frightening (Gilbert et al., 2011) and this must be acknowledged and recognized by the mindfulness teacher, who, like any therapist, needs the ability to stop a client from opening too much, or diving into the pain, rather than just contacting it (Herman, 1997). Practitioners should prepare participants for what to expect and screen for potentially vulnerable individuals.

The intervention involves a degree of work and commitment which participants should understand when they sign up. It can be, as Emma says “exhausting” to do the practices and homework and sometimes she, and others “didn’t want to do it.” Coronavirus notwithstanding however, on the courses and in the study itself, as previously discussed, there was very little dropout, suggesting a requirement for practitioners to be clear about the protocol and necessary adherence before commencement. After the course, some participants were fearful of losing the skills learned and missed their connection with the group, and practitioners might also consider follow-up mindfulness sessions to further support individuals.

There are limitations to this part of the study. The qualitative sample (*n* = 10) was small, and although appropriate for a thematic analysis (Braun & Clarke, 2020) there must be caution in drawing conclusions with a limited cohort (Shaw et al., 2018). Participants were also predominantly white, well-educated women over 55 with breast cancer. While this is similar to other qualitative studies into mindfulness and self-compassion (L'Estrange et al., 2016), it is not representative of the UK cancer population, where more men than women are diagnosed with cancer, where black men are as likely as white men to get the disease, and where cancers are higher in more deprived areas (Cancer Research UK, 2021). The generalizability of this study is limited to the sample itself, which also limits its potential transferability. In its submission to the NHS Long Term Plan, the British Psychological Society suggests increasing access and choice to services for those with psychological difficulties and recommends that the workforce looks to “deliver or enhance therapeutic interventions through a variety of digital methods” (British Psychological Society [BPS], 2020, p. 5) to ensure equitable access. Examining the efficacy, appropriateness, and acceptability of a digitally delivered MBCT-Ca course to help widen that access in a cancer population, would be a valuable future area of research.

Another limitation is that the qualitative interviews may be subject to recall bias (Grimes & Schulz, 2002). Although individuals were asked to recount their experiences of the intervention as a whole and not prompted to examine either positive or negative effects, they were aware that both the course and the study had a focus on compassion, which may have affected their answers. Participant states or traits, which were not examined in this study, may have influenced both the efficacy of the course and its self-reported outcomes and it is not known whether individuals began the intervention with a level of psychological flexibility which made it more likely for them to accept change.

These limitations notwithstanding, I believe this study makes a valuable contribution to Counselling Psychology research, theory, and practice. Half of us will develop cancer in our lifetimes and more people are living longer following a diagnosis, but many individuals may be unaware of the extent of cancer’s psychological and social impact (Foster & Fenlon, 2011). There can also be a feeling of loss and abandonment at the end of treatment, which can exacerbate difficulties, with emotional support being the biggest unmet need in the first year after cancer treatment (Kuyken et al., 2015). The BPS suggests that in psycho-oncology, “strong consideration” be given to qualitative studies with an active involvement from patients, which examine outcomes that look “beyond the narrow confines of symptom reduction to consider the full breadth of what is most useful to service users and cancer professionals” (BPS, 2020, p. 17). This study does that by evaluating a mindfulness intervention in those with cancer and then, hearing the voice of the individual which illuminates and adds a depth to the understanding of mechanisms and processes.

This study also looks at group and individual change, and this can help the profession deliver on its aim of providing holistic, patient-centred care, which is driven by the individual and their cancer pathway, rather than presenting them with a predefined package of care (BPS, 2015). Good quality psychological care in cancer can lower healthcare costs, and improve quality of life (Arving et al., 2013) and hearing the voice of the individual at the heart of research into interventions and outcomes, can enhance that quality further.

4.3.6 Summary of qualitative findings

The qualitative part of the study raised common themes that could not be extrapolated from the quantitative alone and which can help with the development of future interventions. Key to a successful outcome was the motivation of the individual, the explanation of the process and protocol, the safety and trust engendered by an experienced teacher and familiar setting, the benefit of a group dynamic in validating suffering, the awareness and acceptance of pain and self-judgment and the allowing for compassion. Crucial to the change process was meeting distressing thoughts, feelings and sensations with equanimity, empathy and kindness and this study enhanced an understanding of the cognitive-behavioural elements, the psychoeducation, and the group support that allowed for this cultivation of acceptance and self-kindness. Individuals were able to choose where to go with their thoughts and emotions, where previously, they may have reacted instinctively to them with habitual patterns of suppression and avoidance, and this meant they moved towards difficulty with a kindness and curiosity. They “looked at pain differently” (Barbara) and “by going into it, it subsided” (Lucy). They practised ”being with and accepting, rather than pushing away” (Maya). They may have “hated it at the time” because it was “really, really hard”, but it felt “necessary” and took them “slowly, down the path towards enlightenment” (Emma).

4.4 Methodological integrity in mixed methods

An American Psychological Association taskforce examining validity and reliability in mixed methods studies, recommends that researchers prioritise methodological transparency (Levitt et al., 2018). It suggested three steps; be explicit about what benefits are likely to be accrued from mixed methods, be clear about the use and value of a widely recognized design and use explicit commentary on how quantitative and qualitative data has been integrated or mixed. This prevents mixed methods, becoming ‘mixed-up methods’ (Creamer, 2018).

The main argument for using mixed methods in this study was that it resulted in stronger conclusions than could be achieved using a single method. It was both sequential and recursive, enhancing quality and leaving room for innovative thinking. While the quantitative data from the overall sample provided an understanding of reported shifts in concepts, the individual data identified significant and meaningful change in each participant, which helped when examining the processes and mechanisms of that change in follow-up interviews. This meant a dialectical engagement with both quantitative and qualitative strands and an open mindset as to what emerged, sometimes unexpectedly, such as when the quantitative and qualitative data seemed to tell different stories about the same construct.

The design of this study was sequential explanatory, which is particularly useful for explaining relationships and/or findings, especially if they are contradictory (Hanson et al., 2005). This mixed methods design offered the potential for theoretical insights in examining potential differences in the quantitative and qualitative data between, for example, reflection and self-compassion, or self-criticism. One outlier represented a seemingly counterintuitive finding, a significant rise in fears of self-kindness, when others saw a fall. Being able to qualitatively explore this participant’s experience of shame connected to her unpleasant side effects, brought a depth to the study and an understanding of her fear of compassion, which would not have existed with quantitative measures alone. While dissonance made the study more complex, it also enabled a deeper, and more nuanced, understanding of the concepts under discussion. Often, this way of working meant reinvesting time in further literature when unexpected findings arose and trying to be more creative by using different viewpoints.

The findings were presented sequentially; quantitative followed by qualitative, what Hanson et al., (2005) would describe as quant-QUAL, with the participants in the second stage of the study being connected to what emerged in the first. The quantitative data, in the form of scores, had been collected and analysed before the qualitative data, however, the latter did not merely augment the former. While it tended to support the first part of the study, the depth that came from the interviews meant a more iterative process, with integration in the analysis and discussion. Triangulation with both sets of data was achieved by cross-checking assumptions with two supervisors.

4.5 Epistemological position

It is important to be explicit about my epistemological and theoretical lens in this mixed methods study. The post-positivist epistemological stance in Part One acknowledges that there is no objective ‘reality’ in the findings, however, for the study to be of value to those with cancer, practitioners and other clinicians, there was a requirement to see if a perceived change had occurred and this was best assessed using quantitative measures. A critical realist approach helped identify patterns and associations in this data, but complex concepts and relationships cannot be truly captured by responses to standardised measures and qualitative methods were needed to illuminate them. As mine is a constructivist approach, weight was given to the qualitative (Hanson et al., 2005), to prioritise the perception of processes and mechanisms of mindfulness and hear from the individuals themselves, who are not well represented in much of the research in cancer or mindfulness.

However, there was an initial tension within this integration. The selection of participants was based on their reported scores yet being driven in the semi-structured interviews by those same results might have led to a potential bias in the questions, undermining the validity of the qualitative data. My critical realist, constructivist positioning meant questions were asked from a pragmatic perspective, not assuming their comments represented a reality or accuracy, and not challenging participants if their answers seemed to contradict their survey responses. This pragmatism comes from an understanding that scientific concepts can be viewed in different ways, and this is the dialogical approach that mixed methods, and this study, offers.

Part Two explained and explored the concepts and the process of change, by using the depth and richness from the interviews, while being as Braun and Clarke (2019) say, “explicit, thoughtful and deliberate” (p. 594) in the application of Reflexive Thematic Analysis, reflecting on what I was assuming and interrogating whether it held. This meant being able to tell a story about the “so what?” of data, moving beyond description (Braun & Clarke, 2006) and having the flexibility to accept and interpret contradictions. Reflexive TA is already a complex, interactive, and creative process (Trainor & Bundon, 2020), and in a mixed methods approach, it can become even more so, however I believe this makes it of more value to those working in cancer support. McEvoy and Richards (2006) examined a critical realist approach to mixed methods in UK health care settings, using a quantitative survey to identify “clear and consistent patterns”, which were “confirmed and elaborated upon” with findings from the semi-structured interviews, and they concluded that “using both the quantitative and qualitative approaches gave the inquiry a greater sense of balance and perspective” (p. 76). I believe this holds with this study, too.

4.6 Reflexivity

Quantitative studies rely on reliability, validity, and generalizability, some of which is covered in the analysis section in Part One of the study. However, in qualitative research, these terms are not considered appropriate, because of the difference in philosophical positions and purpose (Noble & Smith, 2015). Lincoln and Guba (1985) suggest alternative criteria to demonstrate rigour in qualitative research: truth value, consistency, neutrality, and applicability. These rely on the researcher acknowledging and accounting for any personal biases which may have influenced findings and in this section, I make these clear throughout the study. I outline my personal challenges during the research process, how my experiences may have influenced my perspective and methodology, and what steps were taken to ensure an ongoing reflection enhanced the overall trustworthiness of the study.

4.6.1 Truth value

Initially, I envisaged this study to be a qualitative one, and was reluctant to use quantitative measures, believing there to be a plethora of studies in those with cancer which are based on numbers and outcomes, with little attention paid to the individual. However, on reflection, I questioned whether my aversion to quantitative analysis was based on a perception of the limitations of a forced-choice, self-report questionnaire which fails to reflect nuance, or was linked to my own struggle with statistics. I discussed this with my research supervisor and am grateful she suggested a mixed methods approach, as it revealed a depth and complexity that would not have been seen using one method alone. The unexpected and intriguing results in the quantitative part of the study, for example, a positive relationship between reflective rumination and distress after the mindfulness course, a participant reporting a near-doubling of the ‘fear of compassion to self’ score, an apparent shift in self-critical thinking, benefited from further examination in the qualitative analysis, which mixed methods allowed for.

However, I lack confidence with statistics. I scored the results several times, as well as cross-checking them with a statistician but this part of the analysis took far longer than I envisaged and was considerably more challenging. Perhaps a fear of misinterpretation provided a rigour that I may not have had, were I more comfortable with numbers. Lincoln and Guba (1985) suggest ‘truth value’ in a study can also be established by researchers outlining their personal experiences and suggest using a reflective journal and peer debriefing and I continue to do both.

4.6.2 Consistency

Another of Lincoln and Guba’s criteria is ‘consistency’, which means making a researcher’s decision-making process, with any challenges and issues raised, clear and transparent. One of these challenges for me was how to examine the concepts under discussion in the semi-structured interviews, without influencing participants’ own understanding of their meanings. Quantitative analysis assumed an understanding of ‘compassion’, ‘rumination’ or ‘negative coping’ based on previous research, but there needed to be a linguistic reflexivity in the qualitative phase to ensure individuals explained in their own words what this meant to them, without direction from me. For example, while compassion is thought to be a sensitivity to distress, and a commitment to do something about it (Cole-King & Gilbert, 2011), this may not be how the participants envisaged kindness. I did not want to presume they knew what ‘compassion’ was and tried to elicit an individual understanding of kindness in open-ended, Socratic questions. They were not advised of their pre- and post-intervention on any scores (nor did they ask), and, as above, I did not use them to influence my questioning either.

4.6.3 Neutrality

Throughout, I’ve tried to maintain a degree of reflexive analysis to the issues raised in conducting this research, along with a heightened understanding of the tensions of having an insider/outsider, or dual perspective, but this inevitability affects neutrality, which in Lincoln and Guba’s context is a ‘confirmability’ linked to the researcher’s experiences and perspectives. I chose this research question as someone who has had cancer and who has provided therapy to those with the disease, including at Maggie’s, and because I understand the lack of widespread psychological help. I'm aware that receiving a diagnosis can make you feel like a 'patient', not an individual. That the language around cancer can be one of 'battles', 'victories' and 'being brave' and how easy it can be to feel as though you're 'losing', or not 'fighting' hard enough, which may encourage judgement. Equally, I know much of this is my experience.

Subjectivity isn't removed in quantitative data, but I needed to remind myself throughout this research, of the "seduction of sameness" (Hurd & McIntyre, 1996) when participants' age, background and experiences seemed to mirror my own, and the qualitative interviews were challenging in this regard. I have spent thirty-five years in journalism and know how to detach when a story has personal resonance, but this was not a news interview where I was searching for content and occasionally, I felt the emotion of the interviews more intensely than I felt comfortable with, due in part, to my own experience. This tension between being a former patient and a counselling psychologist offering therapy to those with the disease is, I believe, inevitable and something to sit with, rather than reject. There can be a strength in this dual perspective, which those who have it, urge others to embrace, but which some in the profession, reject (Galgut, 2021).

4.6.4 Applicability

Working in psycho-oncology during this period meant there needed to be clear boundaries about what was research, what was client work and what was personal. The criterion of 'applicability' refers to the consideration that a researcher gives to other contexts and settings and how this may influence their study. My cancer experience is not disclosed during sessions with NHS patients and the individuals taking part in the research were not aware of my background either, or if they were, chose not to raise it. In the screening call beforehand, I advised all participants that the interview was not a therapy session, but inevitably, some became upset when talking about their initial lack of self-kindness and on two occasions, we discussed stopping the interview. Although they declined, I was aware that this created a tension where my role as a therapist urged me to take over, to settle and calm, to help and be alongside. I made sure to check that they had the support and time to process after the interview, while also sending a follow-up briefing sheet with resources attached but there was some guilt that I had opened a box that I could not help close, and I reflected on this with my research supervisor and kept reflective diaries.

4.6.5 Methodological reflexivity

I was grateful to present initial findings to the Psycho-oncology team at the Imperial College NHS Trust, where I was working as a trainee counselling psychologist. The feedback was positive and encouraging, however my placement supervisor, a clinical psychologist, suggested I was perhaps “too reflexive”, “very attached” to the study and may need to be “more dispassionate” and these remarks refocused my attention on the risks of over-interpretation. A methodological reflexivity was required and an understanding that there are limits to what I can and cannot know.

The psychologist also suggested the study had “real merit” and I should not be “in agonies” over the numbers. He had picked up on my frustrations with the small sample size, a methodological issue that can plague other mindfulness studies in cancer and one which I had hoped to avoid. I relied on the ‘gatekeepers’; Maggie’s centre heads and mindfulness teachers, who were asked to put up posters and distribute information sheets. I initially contacted all Maggie’s centres but despite chasing, not all got back to me. Three of the six centres who took part were based in London, with the same teacher who expressed an interest and engagement with the study. I did not have the same response or relationship with others and that may have influenced the number of participants taking part. It also raised the potential for positive bias; if participants are aware their teacher is keen on the research, might that affect their answers? Also, previously working at Maggie’s as a trainee counselling psychologist, might that have influenced that centre head and mindfulness teacher to become more engaged in the research. Although I had left the centre some time previously, it also raises the possibility of my own bias, which I reflected on in supervision.

4.6.6 Ethical issues and coronavirus

There are ethical issues in collecting data during a time when many individuals with cancer may have been facing a new crisis, that of coronavirus, and the analysis of the results needed a heightened sensitivity to context. However, it was also clear that the quantitative data alone would not allow any interpretive leap about whether an external had affected those taking part. While it was frustrating that courses were cancelled due to coronavirus, interviewing individuals who had completed an intervention as the pandemic began, offered a fresh perspective on how they used their newly acquired mindfulness skills. Surely, if mindfulness is to matter, then it needs to hold in the face of difficulty and uncertainty? The journalist in me wanted to focus on this as ‘the story’, the counselling psychologist knew not to drive it. Participants themselves mentioned how they were reacting to the pandemic and how mindfulness was helping without my prompting, and this made the analysis and the study itself, more challenging, interesting and I hope, relevant.

At the time of the recordings, I was recovering from cancer reconstructive surgery, was shielding and was acutely aware of the need for extra self-care. I kept a diary, saw a personal therapist, and limited the interviews to one a day, however I found the individuals’ narratives, with their searing honesty, and accompanying mixture of anger, shame, injustice, pride, love, and kindness, profoundly moving. Whether this is because of my cancer experience or because suffering encourages an empathic response and reminds us of what it means to be human is unclear, but many participants said they were telling me something for the first time or were surprised by their own emotion. I am honoured by their trust and hope I am reflecting their experiences with integrity. Here too, I reflect on what I have learnt from the participants and their struggle to let go of ‘perfect’. Carrying their stories feels like being in possession of a treasured vase and I am fearful of dropping it. What they have taught me is even if that happens, it can be pieced together and hopefully, made into something valuable.

4.7 Concluding remarks

After data collection and analysis, I was asked to host a panel discussion for the BPS 2021 Spring Conference called ‘Living with, and beyond cancer.’ The panellists were a clinical psychologist working in psycho-oncology, a researcher from Macmillan Cancer Support and a counselling psychologist who lives with side effects from the disease. They all warned of a surge in psychological distress among those with cancer, many of whom, in the middle of a Covid pandemic, were living with a disease left unchecked. Operations had been cancelled, treatments postponed, and waiting lists lengthened. Even before the pandemic, more than 20% of cancer patients felt their emotional needs were being unmet (Macmillan Cancer Support, 2019c), yet the gap in the specialist cancer workforce was growing ever larger (Cancer Research UK, 2020). Counselling Psychology has a vital role to play in offering help for the increasing numbers of people trying to manage the psychological challenges that come with cancer, but practitioners need to know what works and why. Mindfulness is not the answer, but it might be part of the solution. Participants spoke to me during the first coronavirus lockdown, and it was notable that although many were unsettled and uneasy, all stressed how valuable mindfulness had been, in helping them cope during unpredictable times.

Cancer can rob you of your health, but can it also chip away at your mental wellbeing and sense of self; there is often guilt, blame and judgment attached to the struggle, and there is a long way to go before services catch up with the demand for support. Mindfulness has been presented as a relatively low-cost intervention which allows the individual with cancer to improve their quality of life (Lengacher et al., 2015). However, while less costly than individual therapy, mindfulness should not be seen as a ‘cheap’ option. It is not risk-free and can produce adverse effects, which screening, correct protocol, and participant preparedness can help ameliorate. It is not necessarily easy to implement either; it involves establishing a place of safety and trust with an experienced and well-trained teacher who is able to guide and manage any emotional distress. However, as shown in this research, if done well, it may shift ruminative thinking and negative coping, and allow for more self-kindness. It can help reframe individuals’ perception of the disease, enable them to notice and accept their suffering and pain with compassion and acknowledge that the uncertainty of dying is part of the complexity of living.

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Appendices

Appendix 1: Ethics Approval

Appendix 1a: Original City ethics approval

Dear Sian

Reference: ETH1819-1443

Project title: Experience of change in rumination and self-compassion in those with cancer following a mindfulness-based intervention

Start date: 29 Sep 2019

End date: 31 Jul 2020

I am writing to you to confirm that the research proposal detailed above has been granted formal approval from the Psychology low risk review. The Committee’s response is based on the protocol described in the application form and supporting documentation. Approval has been given for the submitted application only and the research must be conducted accordingly. You are now free to start recruitment.

Should you have any further queries relating to this matter, please do not hesitate to contact me. On behalf of the Psychology low risk review, I do hope that the project meets with success.

Kind regards

[redacted]

Psychology low risk review

City, University of London

Ethics ETH1819-1443: Sian Williams (Low risk)

Appendix 1b: Ethics amendment: consent to record online

Reference: ETH1920-1325

Project title: Experience of change in rumination and self-compassion in those with cancer following a mindfulness-based intervention

Start date: 29 Sep 2019

End date: 31 Jul 2020

Dear Sian

I have approved your amendment to conduct interviews on a secure online platform.

Wishing you all the best

Fran

I am writing to you to confirm that the research proposal detailed above has been granted formal approval from the Psychology low risk review. The Committee's response is based on the protocol described in the application form and supporting documentation. Approval has been given for the submitted application only and the research must be conducted accordingly. You are now free to start recruitment.

Kind regards

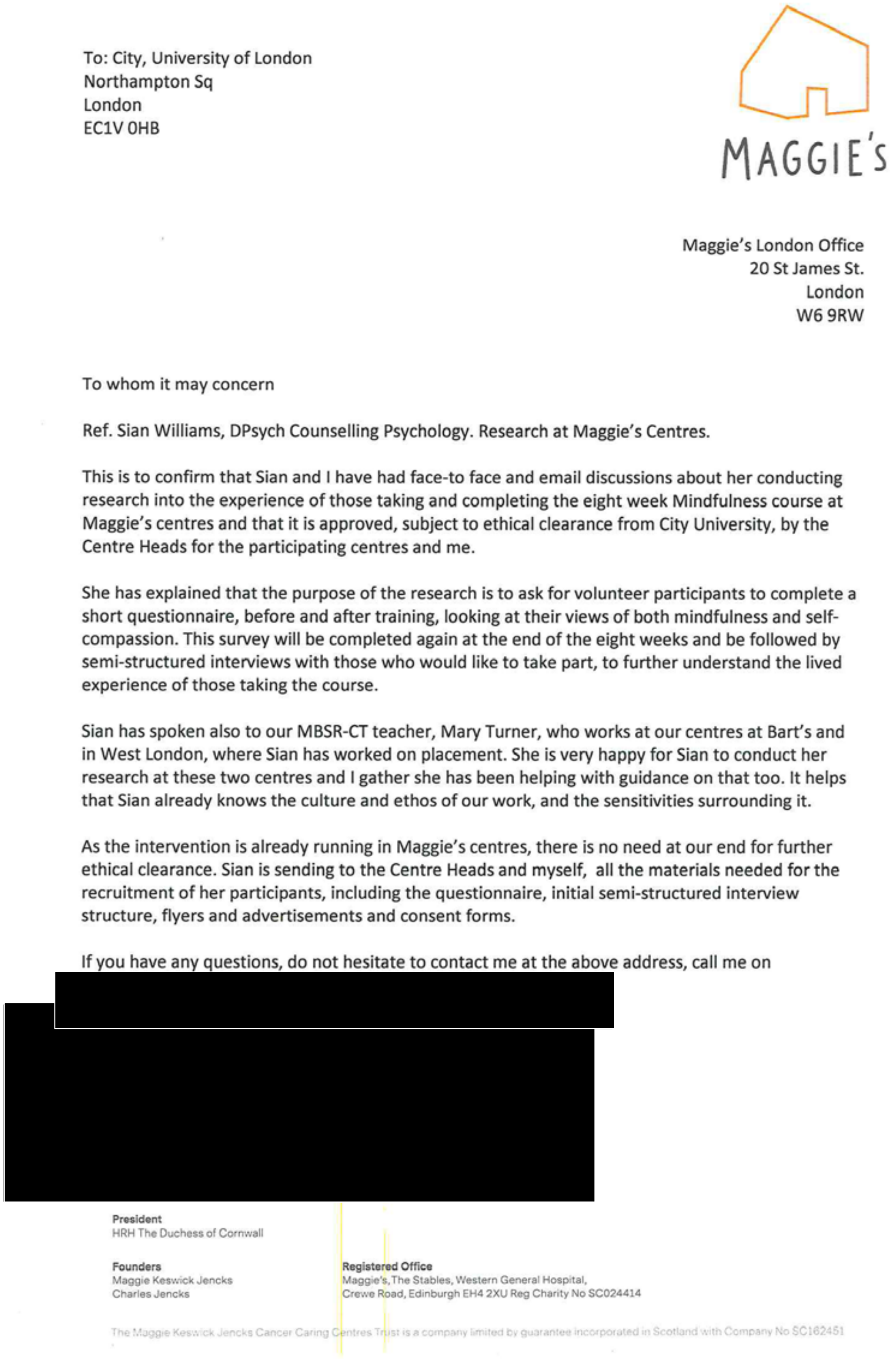
[redacted]

Psychology low risk review

City, University of London

Ethics ETH1920-1325: Sian Williams (Low risk)

Appendix 2: Consent to study: Letter of Approval from Maggie’s Clinical Lead



To: City, University of London
Northampton Sq
London
EC1V 0HB

MAGGIE’S

Maggie’s London Office
20 St James St.
London
W6 9RW

To whom it may concern

Ref. Sian Williams, DPsych Counselling Psychology. Research at Maggie’s Centres.

This is to confirm that Sian and I have had face-to face and email discussions about her conducting research into the experience of those taking and completing the eight week Mindfulness course at Maggie’s centres and that it is approved, subject to ethical clearance from City University, by the Centre Heads for the participating centres and me.

She has explained that the purpose of the research is to ask for volunteer participants to complete a short questionnaire, before and after training, looking at their views of both mindfulness and self-compassion. This survey will be completed again at the end of the eight weeks and be followed by semi-structured interviews with those who would like to take part, to further understand the lived experience of those taking the course.

Sian has spoken also to our MBSR-CT teacher, Mary Turner, who works at our centres at Bart’s and in West London, where Sian has worked on placement. She is very happy for Sian to conduct her research at these two centres and I gather she has been helping with guidance on that too. It helps that Sian already knows the culture and ethos of our work, and the sensitivities surrounding it.

As the intervention is already running in Maggie’s centres, there is no need at our end for further ethical clearance. Sian is sending to the Centre Heads and myself, all the materials needed for the recruitment of her participants, including the questionnaire, initial semi-structured interview structure, flyers and advertisements and consent forms.

If you have any questions, do not hesitate to contact me at the above address, call me on

[redacted]

President
HRH The Duchess of Cornwall

Founders
Maggie Keswick Jencks
Charles Jencks

Registered Office
Maggie’s, The Stables, Western General Hospital,
Crewe Road, Edinburgh EH4 2XU Reg Charity No SC024414

The Maggie Keswick Jencks Cancer Caring Centres Trust is a company limited by guarantee incorporated in Scotland with Company No SC162451

Appendix 3: Research poster

Department of Psychology, City, University of London

MINDFULNESS AND CANCER: RESEARCH VOLUNTEERS NEEDED!

If you're signing up for Maggie's Mindfulness Course, how about taking part in a study about mindfulness and cancer? We'd love to understand the processes involved and you can really help.

If interested, you'll be asked to fill out a short survey before and after the course and some volunteers may be interviewed later if they wish to be. There's complete anonymity and confidentiality. No names are published.

To keep research focused, we will not be able to include anyone with an acute episode of depression, anxiety or another current mental health diagnosis, an addiction to drugs or alcohol, or a recent life crisis like a bereavement.

For more information or to volunteer, please contact Sian Williams at

[redacted]

This study has been reviewed by and received ethical clearance from Maggie's and the Ethics Committee at City, University of London. If you would like to complain about any aspect of the study, please contact the Secretary to the Senate Research Ethics Committee on [redacted] or via email: [redacted]
City, University of London is the data controller for the personal data collected for this research project. If you have any data protection concerns about this research project, please contact City's Information Compliance Team at dataprotection@city.ac.uk

Appendix 4: Example of original consent form in Qualtrics questionnaire

Q1.
Welcome to this survey and thank you for being a part of it.
I'm Sian Williams and I'm currently doing research into whether mindfulness changes our perceptions of living with cancer. It's part of a Doctorate in Counselling Psychology at City, University of London, under the supervision of Dr Trudi Edginton.
I'm looking at whether completing a mindfulness course at Maggie's makes a difference in our thinking and the way we feel about ourselves and
others. The aim of the study is to understand how best to help those who have had or are still experiencing cancer.
You'll be asked some questions about your gender, age, experience, and role, then asked to fill out a questionnaire, which should take around fifteen minutes. You'll be asked to complete it again at the end of the course. All data collected will be anonymous and completely confidential and no individuals will be identifiable. Participation is voluntary and you have the right to withdraw without giving a reason, right up to the date of analysis. After completing the questionnaire, there's an option to participate in the second stage of the research. This is a more in-depth exploration of your experience of the mindfulness course. It involves a one-to-one interview, at a time and date of your choice. If you wish to take part in this second stage of the survey, you will be asked to leave an email address at the end, so I can contact you. Just to repeat, you will remain anonymous and cannot be identified in the final report. If would like to ask me any questions before or after participating in any part of this study, please send an email to sian.williams@city.ac.uk. All personal information you provide will be kept securely and you have the right to ask for it to be destroyed. The study has been approved by City University Ethics Committee.
If you consent to participate under these conditions, please tick below.

Q2.
I agree to the above terms.

Yes

No

Q31.
Thank you for completing the questionnaire. You'll be asked to complete it again at the end of the course.

Just a reminder that this research is designed to further our understanding of what part mindfulness plays in how we think and feel when we're living with cancer. Your help in the second part of the study means we learn more about what any changes mean.

The second stage is an interview with me, on a one-to-one basis, at a time we agree together. This interview is about how the course may have shifted perceptions, it's not an exploration of cancer itself.

If you'd like to take part in the next stage, just leave your email address below. Your details will remain confidential, and you cannot and will not be identified in the final report. If you have any questions, contact me at [redacted]

This study has been granted ethical approval by the City, University of London and will adhere to its standards. You will remain anonymous, you can withdraw at any time up to data analysis and you will get a full debriefing about the study from me, either verbally or by email, afterwards.

Once again, thank you for taking the time to participate in this study. With your help, this research may help us better understand how to safeguard the mental health of those living with cancer.

Thank you. Sian Williams

Yes, I'd like to help further with the study into mindfulness and cancer. My email address is below:

Appendix 5: Example of online amendment to consent

CITY
UNIVERSITY OF LONDON
EST 1894

Updated information on the study at Maggie's

April 2020.
Sian Williams, DPsych Student, City, University of London (Ethics number ETH1819-1443)

Thank you for filling out the questionnaire before and after your Mindfulness course at Maggie's and for agreeing to take part in the next stage of the research, which explores any changes in thinking that you may have experienced.

Thanks too, for leaving me your email address when you consented to this next stage, so we could set a date and time to meet face-to face.

The coronavirus means it's going to be difficult to meet you in person, but I'm still very keen to hear your thoughts and would like to continue the research, with your involvement.

I've currently investigating the most secure ways of doing this online, to protect your privacy, confidentiality and security.

In the meantime, just to reassure you that:

- Interviews will be conducted in private, so that no-one can overhear or oversee.
- All data collected will be anonymized and completely confidential.
- All personal information you provide will be kept securely and you have the right to ask for it to be destroyed.

If you're happy to take part on this basis, please tick the box below and leave your email.

YES, I would like to take part in the next stage ☐ (please tick box)

My email address is	

Then return this form to [redacted] and I'll be in touch shortly. And of course, do email me if you have any questions. Thank you, Sian.

Appendix 6: Mental Adjustment to Cancer Scale

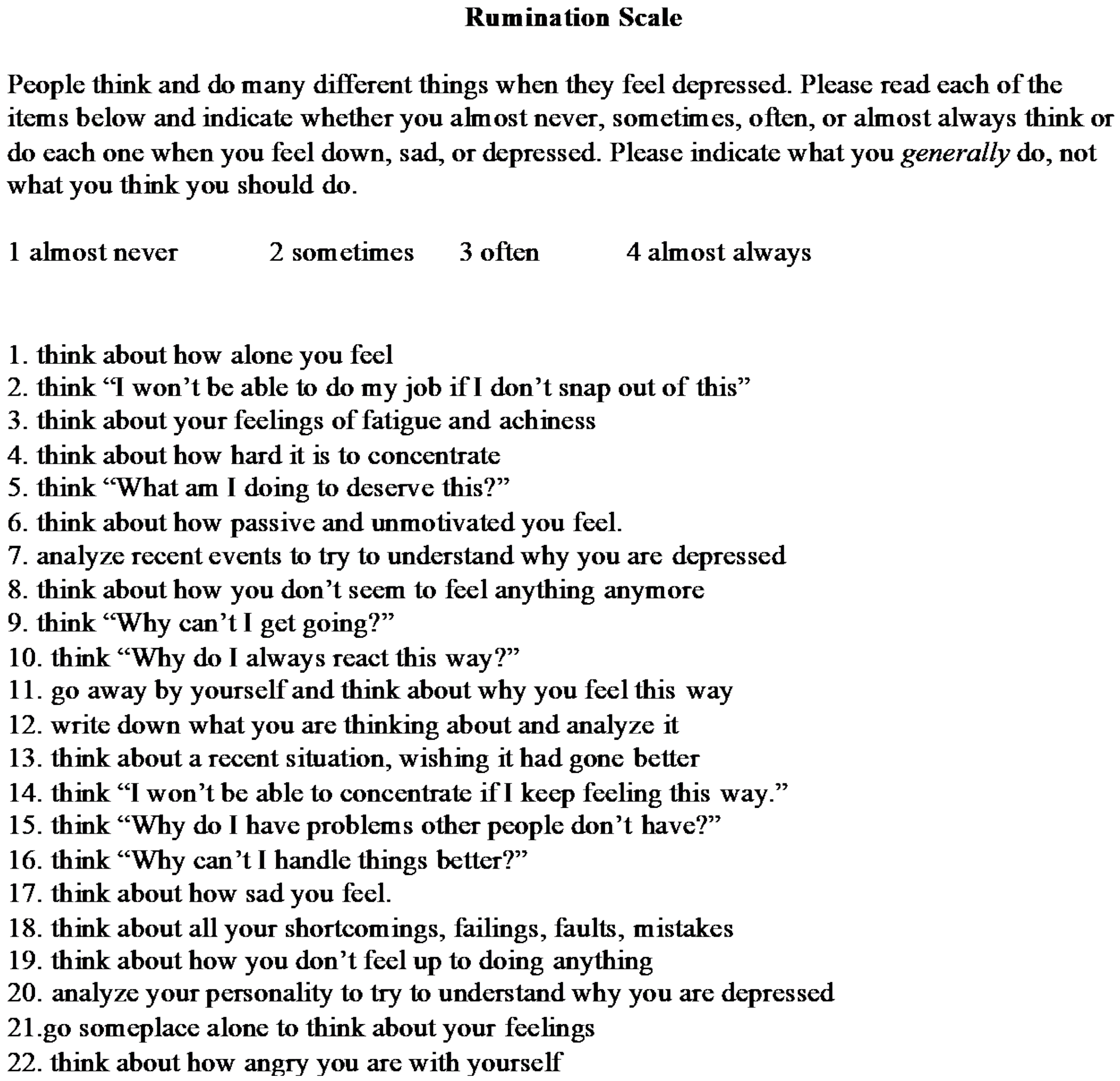
A number of statements are given which describe people's reactions to having cancer. Please circle the appropriate number to the right of each statement, indicating how far it applies to you at present. For example, if the statement definitely does *not* apply to you, then you should circle 1 in the first column.

Mental Adjustment to Cancer Scale	**Definitely does not apply to me**	**Does not apply to me**	**Applies to me**	**Definitely applies to me**
1. I have been doing things that I believe will improve my health (e.g., I have changed my diet)	**1**	**2**	**3**	**4**
2. I feel I can't do anything to cheer myself up	**1**	**2**	**3**	**4**
3. I feel that problems with my health prevent me from planning ahead	**1**	**2**	**3**	**4**
4. I believe that my positive attitude will benefit my health	**1**	**2**	**3**	**4**
5. I don't dwell on my illness	**1**	**2**	**3**	**4**
6. I firmly believe that I will get better	**1**	**2**	**3**	**4**
7. I feel that nothing I can do will make any difference	**1**	**2**	**3**	**4**
8. I've left it all to my doctors	**1**	**2**	**3**	**4**
9. I feel that life is hopeless	**1**	**2**	**3**	**4**
10. I have been doing things that I believe will improve my health (e.g., exercise)	**1**	**2**	**3**	**4**
11. Since my cancer diagnosis I now realize how precious life is, and I'm making the most of it	1	2	3	4
12. I've put myself in the hands of God	1	2	3	4
13. I have plans for the future (e.g., holiday, jobs, housing)	1	2	3	4
14. I worry about the cancer returning or getting worse	1	2	3	4
15. I've had a good life — what's left is a bonus	1	2	3	4
16. I think my state of mind can make a lot of difference to my health	1	2	3	4
17. I feel that there is nothing I can do to help myself	1	2	3	4

18. I try to carry on my life as I’ve always done	1	2	3	4
19. I would like to make contact with others in the same boat	1	2	3	4
20. I am determined to put it all behind me	1	2	3	4
21. I have difficulty in believing that this has happened to me	1	2	3	4
22. I suffer great anxiety about it	1	2	3	4
23. I am not very hopeful about the future	1	2	3	4
24. At the moment I take one day at a time	1	2	3	4
25. I feel like giving up	1	2	3	4
26. I try to keep a sense of humour about it	1	2	3	4
27. Other people worry about me more than I do	1	2	3	4
28. I think of other people who are worse off	1	2	3	4
29. I am trying to get as much information as I can about cancer	1	2	3	4
30. I feel that I can’t control what is happening	1	2	3	4
31. I try to have a very positive attitude	1	2	3	4
32. I keep quite busy, so I don’t have time to think about it	1	2	3	4
33. I avoid finding out more about it	1	2	3	4
34. I see my illness as a challenge	1	2	3	4
35. I feel fatalistic about it	1	2	3	4
36. I feel completely at a loss about what to do	1	2	3	4
37. I feel very angry about what has happened to me	1	2	3	4
38. I don’t really believe I have cancer	1	2	3	4
39. I count my blessings	1	2	3	4
40. I try to fight the illness	1	2	3	4

Watson et al., (1998)

Appendix 7: Rumination Responses Scale



Rumination Scale

People think and do many different things when they feel depressed. Please read each of the items below and indicate whether you almost never, sometimes, often, or almost always think or do each one when you feel down, sad, or depressed. Please indicate what you *generally* do, not what you think you should do.

1 almost never 2 sometimes 3 often 4 almost always

1. think about how alone you feel
2. think "I won't be able to do my job if I don't snap out of this"
3. think about your feelings of fatigue and achiness
4. think about how hard it is to concentrate
5. think "What am I doing to deserve this?"
6. think about how passive and unmotivated you feel.
7. analyze recent events to try to understand why you are depressed
8. think about how you don't seem to feel anything anymore
9. think "Why can't I get going?"
10. think "Why do I always react this way?"
11. go away by yourself and think about why you feel this way
12. write down what you are thinking about and analyze it
13. think about a recent situation, wishing it had gone better
14. think "I won't be able to concentrate if I keep feeling this way."
15. think "Why do I have problems other people don't have?"
16. think "Why can't I handle things better?"
17. think about how sad you feel.
18. think about all your shortcomings, failings, faults, mistakes
19. think about how you don't feel up to doing anything
20. analyze your personality to try to understand why you are depressed
21. go someplace alone to think about your feelings
22. think about how angry you are with yourself

Treynor, Gonzalez, and Nolen-Hoeksema (2003), Cognitive Therapy and Research, 27, 247-259

To obtain scores on this scale, simply sum the scores on the 22 items

Appendix 8: Fears of Compassion Scale

Different people have different views of compassion and kindness. While some people believe that it is important to show compassion and kindness in all situations and contexts, others believe we should be more cautious and can worry about showing it too much to ourselves and to others. We are interested in your thoughts and beliefs in regard to kindness and compassion in three areas of your life:

1. Expressing compassion for others
2. Responding to compassion from others
3. Expressing kindness and compassion towards yourself

Below are a series of statements that we would like you to think carefully about and then circle the number that best describes how each statement fits you.

SCALE

Please use this scale to rate the extent that you agree with each statement

Don't agree at all	0	1	2	3	4	Completely agree
			Somewhat agree			

Scale 1: Expressing compassion for others

1.	People will take advantage of me if they see me as too compassionate	0	1	2	3	4
2.	Being compassionate towards people who have done bad things is letting them off the hook	0	1	2	3	4
3.	There are some people in life who don’t deserve compassion	0	1	2	3	4
4.	I fear that being too compassionate makes people an easy target	0	1	2	3	4
5.	People will take advantage of you if you are too forgiving and compassionate	0	1	2	3	4
6.	I worry that if I am compassionate, vulnerable people can be drawn to me and drain my emotional resources	0	1	2	3	4
7.	People need to help themselves rather than waiting for others to help them	0	1	2	3	4
8.	I fear that if I am compassionate, some people will become too dependent upon me	0	1	2	3	4
9.	Being too compassionate makes people soft and easy to take advantage of	0	1	2	3	4
10.	For some people, I think discipline and proper punishments are more helpful than being compassionate to them	0	1	2	3	4

Scale 2: Responding to the expression of compassion from others

1.	Wanting others to be kind to oneself is a weakness	0	1	2	3	4
2.	I fear that when I need people to be kind and understanding they won’t be	0	1	2	3	4
3.	I’m fearful of becoming dependent on the care from others because they might not always be available or willing to give it	0	1	2	3	4
4.	I often wonder whether displays of warmth and kindness from others are genuine	0	1	2	3	4
5.	Feelings of kindness from others are somehow frightening	0	1	2	3	4
6.	When people are kind and compassionate towards me, I feel anxious or embarrassed	0	1	2	3	4
7.	If people are friendly and kind, I worry they will find out something bad about me that will change their mind	0	1	2	3	4
8.	I worry that people are only kind and compassionate if they want something from me	0	1	2	3	4
9.	When people are kind and compassionate towards me, I feel empty and sad	0	1	2	3	4
10.	If people are kind, I feel they are getting too close	0	1	2	3	4
11.	Even though other people are kind to me, I have rarely felt warmth from my relationships with others	0	1	2	3	4
12.	I try to keep my distance from others even if I know they are kind	0	1	2	3	4

13.	If I think someone is being kind and caring towards me, I put up a barrier	0	1	2	3	4

Scale 3: Expressing kindness and compassion towards yourself

1.	I feel that I don't deserve to be kind and forgiving to myself	0	1	2	3	4
2.	If I really think about being kind and gentle with myself it makes me sad	0	1	2	3	4
3.	Getting on in life is about being tough rather than compassionate	0	1	2	3	4
4.	I would rather not know what being 'kind and compassionate to myself' feels like	0	1	2	3	4
5.	When I try and feel kind and warm to myself, I just feel kind of empty	0	1	2	3	4
6.	I fear that if I start to feel compassion and warmth for myself, I will feel overcome with a sense of loss/grief	0	1	2	3	4
7.	I fear that if I become kinder and less self-critical to myself then my standards will drop	0	1	2	3	4
8.	I fear that if I am more self-compassionate, I will become a weak person	0	1	2	3	4
9.	I have never felt compassion for myself, so I would not know where to begin to develop these feelings	0	1	2	3	4
10.	I worry that if I start to develop compassion for myself, I will become dependent on it	0	1	2	3	4
11.	I fear that if I become too compassionate to myself, I will lose my self-criticism and my flaws will show	0	1	2	3	4
12.	I fear that if I develop compassion for myself, I will become someone I do not want to be	0	1	2	3	4
13.	I fear that if I become too compassionate to myself others will reject me	0	1	2	3	4
14.	I find it easier to be critical towards myself rather than compassionate	0	1	2	3	4
15.	I fear that if I am too compassionate towards myself, bad things will happen	0	1	2	3	4

SCORING
Simply sum the items for each of the 3 scales

Gilbert, P., McEwan, K., Matos, M. & Rivis, A. (2011). Fear of compassion: Development of a self-report measure. *Psychology and Psychotherapy*

Appendix 9: Initial Participant Information Sheet

Study into Mindfulness at Maggie’s

December 2019

Mindfulness and cancer: the experience of those taking the eight-week course at Maggie’s

Ethics number ETH1819-1443
Sian Williams, DPsych Student, City, University of London

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. You will be given a copy of this information sheet to keep.

What is the purpose of the study?

More than half of us will get cancer and sometimes the emotions can be difficult to deal with. Access to help in this area, can be patchy and inconsistent. Mindfulness is said to help with the symptoms of anxiety and depression, which many experience. Maggie’s offers an eight-week course to help develop skills to help manage and respond to any changes, uncertainty and distress caused by living with cancer.

The study will look at whether it manages to do that and what might be responsible for any change. It’ll hear from you about your experience of the course and whether your perspective has shifted after it. The study is part of a Professional Doctorate in Counselling Psychology at City, University of London and may help inform others who are thinking of bringing in similar interventions in other parts of the UK.

Why have I been invited to take part?

You’ve expressed an interest in the course and we think you may be interested in finding out about the processes involved and any changes you may see. Eligibility is based on the following: a) male or female with a cancer diagnosis b) From 25-85 years, c) diagnosed with any type and stage of cancer, c) ability to speak and read English.

The exclusion criteria will be a) an acute episode of depression or anxiety, b) presenting with another mental health diagnosis such as current post-traumatic disorder, psychosis, or a personality disorder c) having an active or recent physical addiction to alcohol or drugs and/or d) an additional acute life crisis such as a recent bereavement within the last 12-18 months.

Do I have to take part?

No, participation is entirely voluntary. It is up to you to decide whether to take part. If you do decide to take part, you will be asked to sign a consent form. All data collected will be anonymized and completely confidential. All personal information you provide will be kept securely and you have the right to ask for it to be destroyed.

What'll happen if I take part?

I'll send you a link to a survey where you'll be asked some questions about your age and background, then asked to fill out a short questionnaire, which should take no longer than six to ten minutes.

After the questionnaire, there is an option to participate in the second stage of the research. This is a more in-depth exploration of the experience of growth following traumatic events. It involves a one-to-one interview, of about an hour, at either Maggie's or at City University, at a time of your choice.

If you wish to take part this this second stage of the survey, you will be asked to leave an email address at the end, so I can contact you. I'll be transcribing the interviews and forming common themes. I'll check them with a Counselling Psychologist, and you'll get the chance to find out what those themes are too before publication. You may, or may not be selected for interview, but just to repeat, those who are, will remain anonymous and cannot be identified in the final report.

The study will begin in January 2020 and finish around May. If you would like to ask me any questions before or after participating in any part of this study, please send an email to [redacted]

What do I have to do if I take part?

Provide brief biographical information, fill out the survey, before and after the mindfulness course and, if you wish to participate further, contact me saying you consent to be interviewed.

What are the advantages/disadvantages of taking part?

You'll get the chance to find out a little more about yourself, help Maggie's and other charities and service providers understand how best to help people in similar circumstances and contribute to the wider knowledge about mindfulness and its effects. The study is from the field of positive psychology and is not designed to distress you in any way. However, you may find yourself talking about reactions or emotions generated by the course, which you may find upsetting. Although I have worked as a therapist at Maggie's for six months, the interview is not a therapy session - I will, however, be able to point you in the direction of help and resources and promise to abide by the strong ethical guidelines dictated by my profession.

What should I do if I want to take part?

If you'd like to take part, please contact me on [redacted]

What will happen to the results?

Anonymity will be maintained if this research is published in peer reviewed journals, related to Counselling Psychology, health, and mindfulness. If you would like to receive a copy of the publication/summary of the results, include details of how I can send it to you. Note that if I am retaining your contact details in order to send you the results once the study has finished, I will require you to explicitly consent to your data being kept for this purpose.

Who has reviewed the study?

This study has been approved by City, University of London Psychology Research Ethics Committee. It has also been approved by the Clinical Lead Psychologist at Maggie's and the mindfulness teacher and centre heads at The Royal Free, Bart's and Charing Cross Hospitals/

What if there is a problem?

If you have any problems, concerns, or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone [redacted]. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is 'The Experience of Rumination and Cancer After an MBI'
You can also write to the Secretary at: [redacted]
Research Integrity Manager
City, University of London, Northampton Square London, EC1V 0HB
Email: [redacted] **Further information and contact details** If you have any further questions or information and do not wish to contact me, do contact my supervisor[redacted] She is the Deputy Director of the Professional Doctorate programme at City, an accredited Mindfulness teacher and has supervised many projects of this kind. **Thank you for taking the time to read this information sheet.**

Appendix 10: Participant information sheet with QR code and link

CITY UNIVERSITY
LONDON

Study into Mindfulness at Maggie's – all you need to know!
Thank you for showing an interest in my study! The QR code above will take you straight to the survey once you point the camera on your mobile device at it. Or get to it here:

https://cityunilondon.eu.qualtrics.com/jfe/form/SV_bvbXacGp8ETpr13

Before you begin, it's important to understand why the research is being done and what it involves. Please take time to read the following information carefully.

What is the purpose of the study?
More than half of us will get cancer and sometimes our emotions can be difficult to deal with. Mindfulness is said to help with these difficult feelings and the course at Maggie's aims to develop skills to manage and respond to any changes, uncertainty, and distress. This study looks at what might be responsible for any shift in thinking. It's part of a Professional Doctorate in Counselling Psychology at City, University of London and may help inform others who are thinking of offering or taking a similar course.

Why have I been invited to take part?
You've expressed an interest and I think you may be curious to find out more. Eligibility is based on the following: a) male or female with a cancer diagnosis b) From 25-85 years, c) diagnosed with any type and stage of cancer, c) ability to speak and read English. You won't be able to take part if you have an: a) acute episode of depression or anxiety, b) another mental health diagnosis such as current post-traumatic disorder, psychosis, or a personality disorder c) active or recent physical addiction to alcohol or drugs and/or d) acute life crisis (e.g., a recent bereavement within the last 12-18 months.)

Do I have to take part? Participation is voluntary. All data collected is anonymized and completely confidential. You can withdraw from the study and have your data destroyed without being penalised or disadvantaged in any way, up to the time when the data is anonymised and analysed. All personal information is kept securely, and you have the right to ask for it to be destroyed.

What'll happen when I take part? Once you click on the link above, you'll be asked some brief questions about your age and background, then you'll be asked to fill out a short questionnaire. The whole thing shouldn't take longer than ten minutes. Once the mindfulness course is over, I'll send you a link so you can repeat it. After completing the questionnaire, there's an option to participate in the second stage of the research. This is an interview with me, of around an hour, at either Maggie's or at City University, at an agreed time and date. You'll be asked to leave an email address so I can contact you. You may, or may not be selected for interview, but just to repeat, you'll remain anonymous and won't be identified in the final report.

What do I have to do if I take part? Provide brief biographical information, fill out the survey, before and after the mindfulness course. Then, if you wish to participate further, leave your email address so I can contact you.

What are the advantages/disadvantages of taking part? You'll get the chance to find out a little more about yourself, help Maggie's and other charities and service providers understand how best to help people in similar circumstances, and contribute to the wider knowledge about mindfulness and its effects. Just to emphasize that the study is not designed to distress you in any way, and I will abide by the strong ethical guidelines dictated by my profession. If you get upset, I'll direct you to the appropriate resources.

What should I do if I want to take part? Just click on the link!

What will happen to the results? Anonymity will be maintained if this research is published in peer reviewed journals, related to Counselling Psychology, health, and mindfulness. If you would like to receive a copy of the publication/summary of the results, include details of how I can send it to you. Note that if I am retaining your contact details in order to send you the results once the study has finished, I will require you to explicitly consent to your data being kept for this purpose.

Who has reviewed the study? This study has been approved by City, University of London Psychology Research Ethics Committee and Maggie's Lead Consultant Clinical Psychologist.

What if there is a problem? If you have any problems, concerns, or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure by phoning [redacted] and asking to speak to the Secretary to Senate Research Ethics Committee, informing them that the name of the project is 'Exploring the relationship between compassion, mindfulness and cancer.' You can also write to the Secretary at: [redacted]. Research Integrity Manager. City, University of London, Northampton Square London, EC1V 0HB [redacted]

Further information and contact details
If you have any further questions and do not wish to contact me, do contact my supervisor [redacted]

Thank you for taking the time to read this information sheet. Sian Williams

Appendix 11: Interview Schedule

Question areas (with possible prompts)

1. Expectations of mindfulness before the course

2. Experience of change and whether intentional

3. Impact of change – personally/broader

Introductory questions (open):

Tell me about why you wanted to do the mindfulness course?

What were you expecting?

What would you say your mood was prior to starting?

Pre-course

1. Can you give me an example of your thoughts when you began the course?
2. How were you dealing with your cancer at the time?
3. How did it affect you? - At work/home
4. How did you cope with that? - At work/home
5. What sort of support did you receive? - At work/home/medically
6. Who did you talk to about it? - Why - what did you say – how did talking about it affect you?
7. What were your thoughts when you began the course? About the others – the commitment – the thinking behind it?
8. What did you expect would happen during/after?

Experience of change

9. How did you feel you changed as a result of what you'd experienced? (Then examine 5 areas)

- If you had brooding thoughts – did they change/diminish/increase?
- What about compassion towards self/others?

- Relating to others in and out of group – closer, increased connections?

- Appreciation of life increased? How?

- Personal strength increased? How?

- New possibilities – what?

10. What was the impetus for that change?

- How did you notice?

- Were you also still experiencing negative impact?

11. How did you feel your personality influenced the change?

- Optimistic? Altruistic? Coping strategies? - Background impact - family/culture/spirituality traits

Impact of change

12. What did you learn about yourself and your life?

- How deal with loss/change/challenges now?

13. Perception of stressor changed?

- What meaning do you attach to having cancer now?

- How make sense of it?

14. Thoughts when you needed help?

- Negative results?

- Challenges? (Emotional/physical toll?)

- Will you continue mindfulness? What has it given you?

Supplementary

15. How could other individuals/organizations help in understanding positive change through mindfulness?

16. What advice would you give to those considering it?

17. How do you look back on the training now?

Appendix 12: Debriefing letter

Dear x,

Thank you for taking part in this study and for giving me your time in the interview. The general purpose of this research is to see if there's a connection between brooding thoughts, self-compassion, and low mood in those with cancer before and after a Mindfulness-Based Intervention. In this study, you were asked to rate your emotions on a questionnaire, and while providing valuable insight, it can only give a limited picture of what you've noticed.

Hearing you describe the changes will help me better understand the processes involved. The results from this study will inform others who may be thinking about bringing in the intervention into their practice, and individuals who'd like to know what may be involved and how it can shift how they feel.

If you feel especially concerned about anything raised in the interview, please feel free to contact me at [redacted], or my supervisor at City University [redacted]. As you know, Maggie's is an excellent resource for further help, providing both individual therapy and other supportive groups, but you may also choose to get further support from charities such as Macmillan Cancer Support https://www.macmillan.org.uk. This website gives details of all other cancer charities offering help, including for specific types of disease or different groups http://www.cancernet.co.uk/supportgroups.htm

Thank you again.

Additional Reading:

Bauer-Wu, S (2011) *Leaves falling gently*. *Living fully with serious and life-limiting illness through mindfulness, compassion, and connectedness.* New Harbinger, California.

Bartley, T., & Wiley InterScience (Online service). (2012). *Mindfulness-based cognitive therapy for cancer: Gently turning towards*. Chichester, West Sussex: John Wiley & Sons.

Appendix 13: Participants' Sociodemographic Characteristics

Characteristic	Number *(n)*	Percentage *(%)*
Gender		
Female	22	91
Male	2	9
Age		
45-55	11	50
Over 55	11	50
Ethnicity		
White British	15	68
Any other white	5	23
Chinese	2	9
Main language at home		
English	19	86
Missing	3	14
Employment		
Full time	4	18
Part time	5	23
Self employed	2	9
Unemployed	1	4.5
Homemaker	1	4.5
Retired	8	36.5
Too ill to work	1	4.5
Education		
Secondary school	2	9
College	5	23
University	6	27
Post-graduate	8	37
Prefer not to say	1	4
Mindfulness location		
St Barts, London	8	36.5
Charing Cross, London	4	18
Royal Free, London	4	18
Cambridge	2	9
Newcastle	3	13.5
Dundee	1	4.5

Appendix 14: A 15-Point Checklist of Criteria for Good Thematic Analysis Process (Braun & Clarke, 2006)

Transcription	1.	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for ‘accuracy’.
Coding	2.	Each data item has been given equal attention in the coding process.
	3.	Themes have not been generated from a few vivid examples (an anecdotal approach) but, instead, the coding process has been thorough, inclusive, and comprehensive.
	4.	All relevant extracts for all each theme have been collated.
	5.	Themes have been checked against each other and back to the original data set.
	6.	Themes are internally coherent, consistent, and distinctive.
Analysis	7.	Data have been analysed rather than just paraphrased or described.
	8.	Analysis and data match each other – the extracts illustrate the analytic claims.
	9.	Analysis tells a convincing and well-organised story about the data and topic.
	10.	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11.	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12.	The assumptions about TA are clearly explicated.
	13.	There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent.
	14.	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15.	The researcher is positioned as *active* in the research process; themes do not just ‘emerge’.

(Braun and Clark, 2006, p37)

Appendix 15: Tentative model for potential codes/candidate themes

Candidate themes	Codes/ideas/aspects
Preparedness for mindfulness	Openness to idea/previous intent Time/resources to do it – those who are middle class, secure? Expectation of relaxation, 'airy fairy', TM But harder than expected - difficulties – blocks/week 6 Affected by lockdown/comorbidity
Awareness of rumination	Noticing/observing/reflecting on; Automatic nature of brooding patterns Driven-doing (busy) Context of illness (need to be strong/social comparison) Threat - fear of recurrence Worrying about worrying Self-criticism/perfectionism/people-pleasing
Group solidarity	Common humanity – not just me Experience of belonging - connectedness Validation of experience Individual not patient Context of Maggie's important Teacher holding group together
Bodily awareness	Recognition of felt bodily senses Holding pain in balance – leaning into it Difficulties of sitting with suffering What worked - Body scans and Breathing techniques Discovering strengths in challenge
Mindful skills	'Emergency' mindfulness - toolkit Gardening/painting/knitting/reading = mindful but not necessarily mindfulness practise – the everyday but 'Switching off', 'emptying mind' idea not mindfulness? And when feels like 'homework' or a chore
Agency around compassion	'Deserving' of kindness (but still 'guilty' sometimes) Cancer 'a relief' from doing Noticing/accepting kindness from others and feeling when absent Lowering expectations of self Not worrying about smaller things Altered focus on getting better Slowing down
Evolving change	Self-reflecting - less irritable/calmer and Self-regulating - less reactive Effects on family/daily living Effects on interpretation of lockdown Confounding: religion, lockdown, etc

Appendix 16a: Example of early theme development – participant transcript

SPEAKER1: If you had any brooding thoughts or ruminative thoughts did you notice whether they changed, or diminished or increased during the mindfulness?	
SPEAKER2: Yes, they do. They definitely do. Yes. Yes. I feel calmer, I feel more clearheaded. I'm less irritable...	Recognising change in negative thinking
SPEAKER1: Oh, sorry, I didn't get that word.	
SPEAKER2: Yes, less irritable? And more likely to approach things philosophically and calmly. That's definitely the case. Rather than just reacting and getting cross, so I'm living with my husband and my son, who's 18...and when I'm practicing every day with the mindfulness, it's it's easier to take take things that happen and I think when there are things that would normally irritate or frustrate or make you feel low, it's easier to respond. I find myself responding in a much more positive way, which helps them, and they respond in a positive way. And, you know, you get on an upward upward spiral rather than downward.	Awareness of previous negative coping Noticed by others – reciprocity of positive reactions Needs to be every day. Observing own reactions – acceptance? Recognizing progression? (spiral)
SPEAKER1: Mmmm	
SPEAKER2: I know it's all there. I've not practiced it as much as I would like, but I've got a folder of all my, all the stuff from the course and all my responses because I did do that diligently and quite well, I thought, at the time. And I practiced the mindfulness, and I wrote, I, I wrote in the in the material and I've got that all still in a folder and I need to revisit it probably, to remind myself of how useful it is. Yeah. I mean, the last few weeks I've been in bed a lot and not very well. Ummm...but now I'm better. I would like to get back into practicing a bit more. Definitely	Guilt/fear over not practicing – mindfulness is temporary? Need to be diligent/healthy for it to work Tasks/homework of m'ness, otherwise derailed
SPEAKER1: So how then would you describe how you approached difficulties or frustrations before the course...	

SPEAKER2: ... umm before....	
SPEAKER1: and then after the course?	
SPEAKER2: Yeah. Not, not particularly well I suppose, ummm on the whole, those feelings of... you know, irritation and I tend to worry quite a lot. And what I can do now is I can switch my mind off and not feel that... I can switch it off totally and think about other things or just, just you know, listen to music. Whereas before I found it really difficult to just turn my mind off. When I started the course I thought, this is amazing! This is exactly what I need. I really did enjoy, and it was exactly what I needed, umm	Recognising past rumination/worry. Is mindfulness = switching off/distraction? Expectation – men's is what is needed
SPEAKER1: When you talk about turning your mind off, what is your mind doing?	
SPEAKER2: I suppose it's thinking things that.... umm, I suppose it's just.... it's just fretting and worrying...trying to sort, I just try to sort stuff out in my mind, but it never, never really works...although I guess sometimes it does. But going, going over and over the same, just the same thing, isn't it? It isn't useful? Umm, so yeah, it's hard to switch it off, especially at night-time I think, if I can't sleep, if I'm knackered in the day, because I'm not very well, I can't sleep at night. But then I can put my headphones on and either listen to music or I'll listen to the whole of the book, oh it's Tricia Bartlett, and listen to the... she's the one that I used on my iPod, and I'll listen to the practices. And I've got the whole book that I've downloaded. And I've listened to, I've read, I've listened to the whole of the book, throughout the course and afterwards.	Awareness of fruitlessness of worry Good description of rumination Again – distraction? But following MBCT-Ca course Mindfulness can be listening to music
SPEAKER1: And would you notice do you think, any change in yourself? You mentioned the sort of the.... that you thought you were less irritable if you practiced the mindfulness. But what about a change in how you saw yourself?	
SPEAKER2: Oh, yeah, yeah. I was definitely much kinder to myself. That was a big thing, I remember now, much kinder,	Noticing shift in compassion to self and others

and kinder to other people? So, if I was having a bad day, my expectations of what I'm achieving in that day, yeh, just take it easy and then tomorrow's another day, that, that really helped.	Lowering expectations of achievement Being in the moment/present
SPEAKER1: How did mindfulness then help you with that shift?	
SPEAKER2: It's, it's... the idea that you can just be kind to yourself and er...not worry, it really helps me not to worry actually, it helped me to appreciate to be more positive, you know that thing where you look back on your day and you find three, you know, three things that you can feel positive about? And I did a lot of the actions, so I like, I like gardening, getting outside and going to a friend's allotment and umm... yeah, just trying to... just getting better really and refocusing on myself and not feeling guilty about doing that. Think that's how it really helped.	A new idea – self-compassion Greater appreciation of small things Mindfulness in everyday activities Previous guilt about self-focus
SPEAKER1: And I haven't done the course. So just...can you explain to me how mindfulness helps you do that? What it is about it? What's the process that enables the	
SPEAKER2: The process of mindfulness? Umm... I think it's switching off your mind is the first thing, in that you focus on your body and the sensations in your body and the feelings and allowing... if you feel not so good, just allowing that to be there, umm... just, if we' d done this interview...I know we couldn't because I wasn't well. But, straight after the course I would have remembered all the phrases and because I've not practiced as much as I would have liked it, it's, it's a bit more distant in me in my, in my mind now. It's just pausing, interrupting a thread of thought is very good because quite often that's it is a worry. It's a kind of fretful thought. So, stopping that and then just concentrating on what you're doing and sensations and things around you and not being stuck in your head, I was very stuck in my head actually before and I'm not, not so much now. Yeah, I feel like I can function in a slightly different way...	Switching off mind – distraction rather than attending to difficult thoughts? Recognising somatic/sensations Guilt from not practicing – self-criticism? Being rather than doing?

Appendix 16b: Example of one participant’s themes (written on A5)

[redacted]

Appendix 16c: Example of theme development across all participants (A5)

[redacted]

Appendix 17a: Research logs: design timetable

Appendix 17b: Research logs: timeline/consents 2019-2020

email to SC	03/04/2019	following chat with SC at West London, and tentative approval for study, asking for contact for MT mindfulness teacher to discuss idea further
phone chat with MT	05/04/2019	engagement with MT plus sharing papers on compassion/mindfulness
email LH	10/04/2019	first contact with LH, clinical lead at Maggie’s, re project
meeting LH	20/05/2019	meeting with LH
call LH	13/06/2019	further phone conversations
email TE	18/06/2019	switch in supervisor – TE
email TE	03/07/2019	rethinking qual/quant email with TE
meeting TE	03/07/2019	deciding to stay with mixed methods

approval letter LH	12/07/2019	LH approval letter for research
research prop to LH	13/07/2019	LH sent research prop to agree
approval support SC	15/07/2019	SC approves for W London
email to MH	17/07/2019	email MH for Barts approval
email TE	12/09/2019	ethics sent to TE; meeting arranged
email LH	18/09/2019	SW requests extending to 3 London centres - LH agrees
email MT	12/09/2019	survey questionnaire sent to MT
email MT	15/09/2019	MT approves questionnaire and agrees to pilot
email RV	18/09/2019	RV copied in by LH and emailed
email MT	16/09/2019	MT confirms date change from Oct - Sept
email RV	27/09/2019	response and approval from RV
email MT	02/10/2019	MT conforms all 3 centre heads on board
email MH	04/10/2019	MH finally confirms in writing Barts
chat LH	31/10/2019	LH agrees expansion, approves Dundee and other centres
letter for LH	01/11/2019	LH agrees letter and sends to other centres
meeting TE	04/11/2019	TE agrees expand to include more centres
email MT	05/11/2019	MT confirms dates for Intro to M classes

email MT	13/11/2019	MT receives laminated posters/participant info
email RV, SC, MH	16/11/2019	centre heads agree receipt of info for introduction to men’s courses and putting up posters/informing
email SC	07/11/2019	SC approves Manchester
email CM	08/11/2019	No foulness Oxford
email KV	04/11/2019	KV approves Newcastle
Qualtrics training	04/11/2019	3-hour Qualtrics training for questionnaire
link for pilot	04/11/2019	Qualtrics link sent for feedback from visitors to SC/MT
email SH	15/11/2019	Cheltenham already running - approach again in NY
email LP	18/11/2019	LP agrees Cambridge
Flyers	18/11/2019	flyers to Dundee, Manchester, Newcastle, with participle info sheets and letter
Qualtrics pilot	18/11/2019	followed up with SC/MT
Qualtrics survey	18/11/2019	sent to TE and back to SE to check - SE helps redraft
email to LP	18/11/2019	Cambridge approval - email with flyer/participant info guidance sent
sent survey to 7 centres	19/11/2019	Link to survey with request to send to centre visitors to pilot survey
contacted Dundee	24/11/2019	two mindfulness courses about to run. Sent all details
attended barts	25/11/2019	spoke to mindfulness teacher (MT)
WL -cards and flyers distrib	27th/11/2019	west london, info distributed for NY course

TE suggests title change	29/11/2019	email - change to ‘exploring relationship…’
LH Dundee course starts	03/12/2019	no responses to survey requests!
First participants contact	05/12/2019	three people email directly to Begin survey. We’re off
LH says more courses spring	19/12/2019	no participants from her two courses - more follows in spring - follow up
Pilot link error	19/12/2019	some centre heads still sending pilot link NOT live link. Emails to all
Mancs course starts 08th	20/12/2019	SC and MJ confirm sending link to participants
email to TE	18/12/2019	update on slow response so far and inability to compare/contrast individual pre/post
email to 15 centre heads	19/12/2019	reminder that survey live, with link and info sheets
email to all Maggie’s centres	20/12/2019	Edin, Glasgow, Dundee, highlands, fife, Notts, Swansea, oxford, Lanarkshire, Cambridge, Merseyside, forth valley, Cardiff, Oldham, Aberdeen
Qualtrics catch up	10/01/2020	SE talks through responses so far and how to display. One Q changed to accept multiple answers. One participant completed twice. 11 responses completed, 8 partials
reminders to n'castle, cambs	10/01/2020	Reminder to London centres, Cambs and N’castle that participants should fill out whole survey
cambs course agreement	03/02/2020	confirmation that Cambs course starting
Qualtrics questionnaire	02/02/2020	engagement with SE Qualtrics trainer about post questionnaire - excluding q about have you completed course before and tweaking introduction and end of survey. Request to leave email again
email to TE	29/02/2020	email to TE about including diaries and whether needs new ethics
email to foulness teachers	03/03/2020	contact MT,KG,LH,CM, SC to ask to distribute questionnaire for post survey
email to participants	04/03/2020	contacting participants who failed to finish questionnaire, nudging them

email TE	06/03/2020	request for a meeting to discuss failed methodology
email Angie Cucchi	09/03/2020	request for a call to discuss failed methodology. Call booked.
email TE	26/03/2020	request for a meeting to discuss failed methodology
email to foulness teachers	18/03/2020	reminder to teachers to remind participants to complete 2nd stage questionnaire
email to participants	29/03/2020	suggesting interviews would not be face-to-face - and that was exploring alternatives
ethics amendment	30/03/2020	ethics amendment to conduct online interviews ETH1920-1325
email to TE	02/04/2020	teams meeting with TE to discuss failed methodology. TE agrees to review my rewritten version ASAP
email to TE	08/04/2020	TE sends back methodology with suggestions. SW asks for help interpreting statistics (and 11/04)
amendment approved	09/04/2020	online interviews approved by Fran Smith
email to participants	10/04/2020	new consent forms to sign, to agree to online interviews for those who’d consented to face-to face
email from TE	15/04/2020	TE recommends Andy Field books and suggests going thru SPSS data together
email to TE	17/04/2020	request for help in identifying best participants for semi-structured interviews
emails to SW	18/04/2020	participants sign new consent form for online
email from TE	22/04/2020	TE sends links to books and suggests joining mixed methods group, meeting arranged
TE teams meeting	24/04/2020	TE meeting going through SPSS to determine meaningful stats
Reliable Change Index	25/04/2020	RCI carried out by SW to identify participants showing most signif pre/post change. 10 identified and contacted
briefing calls	25/04/2020-20/06/2020	briefing calls scheduled with 10 participants

zoom interviews	01/05/2020 - 24/06/2020	interviews recorded with 10 participants

Appendix 17c: Research logs: thesis timeline: collection/analysis 2020/2021

Phase 1 Data collection		
Quant data collection	1/1/20	1/3/20
Quant data completion	1/3/20	20/3/20
Initial analysis and RCI	21/3/20	30/3/20
Qual data collection	1/4/20	1/5/20
Qual transcriptions	1/5/20	1/8/20
Phase 2 Analysis		
Prelim quant findings	1/8/20	1/11/20
Prelim qual analysis	1/11/20	1/12/20
Data saturation	1/1/21	1/2/21
Codes/themes	1/2/21	14/2/21
Candidate themes	14/2/21	28/2/21
Phase 3 Writing up		
Introduction	1/3/21	1/4/21
Send intro to TE	2/4/21	19/4/21
Lit review	2/4/21	19/4/21
Methodology	20/4/21	3/5/21
Analysis	3/5/21	17/5/21
Results	17/5/21	7/6/21
Discussion	7/6/21	21/6/21
Reflexivity	21/6/21	5/7/21
Completing thesis	5/7/21	30/8/21

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Section C: Professional Components: Case study and process report

Cultivating self-compassion in a survivor of sexual abuse: a pluralist approach

Section D: Journal Article

For: The European Journal of Cancer Care

Mindfulness Based Cognitive Therapy for Cancer: impact on negative coping, rumination, and fears of compassion

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