"Eternity in an hour…." Exploring the role of mindfulness with patients receiving Palliative Care – an interpretative phenomenological study.

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"If you die before you die then you won't die when you die."

Anonymous

"Life, not death, is the great adventure."

Sherwood Anderson

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Declaration

I hereby declare that the work submitted in this dissertation is the result of my own investigation, except where otherwise stated.

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Abstract

Background: Rates of psychological distress in patients facing end-of-life and receiving palliative care are significant. The prevalence rate for all mood disorders in one meta-analytic study was 29% (Mitchell et al., 2011). Interest in mindfulness meditation has increased exponentially over the past decade (AMRA, 2020). Meta-analyses in healthcare have consistently demonstrated increases in positive mood states and quality of life (Gotink et al., 2015). Few studies have explored the role of mindfulness with patients receiving palliative care. When they have, the mindfulness training component has usually been brief. Due to the growing popularity of mindfulness, patients who require palliative care will increasingly have had some exposure to mindfulness before becoming seriously ill. This study sought to pre-empt this societal shift. **Aim:** To explore the role of mindfulness, especially in relation to symptom burden, with patients who had been practicing mindfulness for a minimum of six months prior to recruitment. **Method:** Four participants met the inclusion criteria, and each engaged in a semi-structured interview. Interviews were analysed using Interpretative Phenomenological Analysis (IPA; Smith et al., 2009) to understand the psychological essence of their experiences. **Findings:** Four superordinate themes were identified: i). An altered relationship to pain; ii). Regulating thoughts and emotions; iii). A paradigm shift; and iv). Cultivating and sustaining mindfulness. These themes reflect previously proposed 'mechanisms of mindfulness' (Hölzel et al., 2011; Vago and Silbersweig, 2012) but also represent some novel findings within a palliative care context. For example, mindfulness appeared to inform a more appropriate use of medication and also impacted patients' relationships in positive ways. These themes are discussed in relation to the existing literature. Finally, the limitations of this study along with implications for future clinical practice and research are outlined.

Glossary

The following is a list of common terms used:

Body Scan	focusing attention for brief periods of time on different regions of the body; usually from a lying down position
Breakthrough pain	pain that is experienced despite regular pain medication
Cultivation	from agriculture; slow growth and development
Discernment	skilful weighing up of different options
Embodiment	present moment awareness reflected in person's presence
Emotion regulation	managing one's (internal) emotional experience
Grounding	usually a deliberate and effortful reorienting of attention to the body
Guidance/guiding	verbal instructions related to mindfulness practice
Meditation	from 'meditare' (to measure); take inward measure; reflect
Mindfulness	the deliberate cultivation of kindly awareness
Mindfulness-Based	usually refers to learning mindfulness in an eight-week format
Paradigm	from mathematics; a (new) way of viewing things
Practice	formal periods of mindfulness
Rumination	obsessive thinking

List of Abbreviations

The following is a list of abbreviations used:

CBT	Cognitive Behaviour Therapy
FA	Focused Attention
fMRI	'functional' Magnetic Resonance Imaging
IASP	International Association for the Study of Pain
MBCT	Mindfulness-Based Cognitive Therapy
MBI:TAC	Mindfulness-Based Interventions Teaching Assessment Criteria
MBSR	Mindfulness-Based Stress Reduction
OA	Open awareness
PRN	'pro re nata' or 'as required' medication

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1. Introduction and Literature Review

“For the secret of the care of the patient is in caring for the patient.”
Francis W. Peabody (October 21, 1925; cited in Davidson, 1993, pp.817)

There are many ways to care. However, Francis W. Peabody’s ‘secret’ is perhaps truer than ever in the context of increasing specialisation in healthcare and medicine. Technological and advanced medicine meet their limits with the dying person in palliative care. So too do we who offer such care (Kearney et al., 2009). Mindfulness not only offers a millennia-old method to care for ourselves as healthcare professionals but also a way for patients to participate in their own healing. This remarkably makes mindfulness a shared practice that goes beyond professional boundaries (Buber, 1958). It is noteworthy that the words for ‘whole, health, healing’ all share the same etymological root. When one considers that ‘mindfulness’ could equally be translated as ‘heartfulness’ (Santorelli, 1999), there appears to be something intrinsically wholistic and caring about the practice of mindfulness.

This introductory chapter begins with a general background to mindfulness and the medical specialty of palliative care, followed by a reflexive statement that explains my interest and motivation in bringing these topics together in this thesis. First I will define ‘mindfulness’ and outline some of the difficulties with this. In the next section I will seek to locate ‘mindfulness’ in relation to its Buddhist origins and its contemporary socio-cultural context.

1.1 Mindfulness

1.1.1 Definition(s)

There is no single widely accepted definition of mindfulness (Van Dam et al., 2018). Perhaps this should be unsurprising, given its wide breadth of meaning and use in different contexts. Debate about how mindfulness should be defined is ongoing. One of the reasons for this seems to be that researchers differ on their own individual definitions of mindfulness, depending on their own backgrounds, interests and understanding.

Perhaps the most common ‘operational’ definition of mindfulness is that attributed to Jon Kabat-Zinn (1994, pp.4): “Mindfulness is the awareness that arises when we pay attention, on purpose, in the present moment, nonjudgmentally.” This has developed in recent years with the phrase “…to things as they are” (Williams et al., 2007, pp.47) and more recently with the phrase, “in the service of self-understanding and wisdom” added to the end of the definition (Kabat-Zinn, 2017c, para.2).

Mindfulness has also been called a ‘paradoxical’ approach to suffering (Shapiro et al., 2018; Kabat-Zinn, 2013; Williams & Penman, 2011). The spirit of “investigation” of paradox aligns well with mindfulness, where a person is encouraged to both investigate and trust their experience of the practice. If a person experiences an improvement in their suffering, it is more likely due to a willingness to first accept and allow experience to be as it is before exerting any need to coerce, control or change it. The practice of mindfulness therefore, offers a framework in which a person can choose their responses to whatever is happening, internally or externally.

Further to Van Dam et al.’s (2018) recommendation to avoid conceptual ambiguity and move away from broad umbrella terms of ‘mindfulness’, I would like to outline a definition of mindfulness that represents practice and understanding in this study. This also includes outlining the concepts, attitudes and practices (Saunders, 2020)[1] that participants in this study were invited to engage in.

The operational definition of mindfulness guiding this study was that of ‘the active cultivation of kindly awareness’. This definition reflects the author’s own understanding and experience of teaching mindfulness in palliative care. The table below sets out those aspects of the practice that were most salient in the teaching process, particularly with the participants who had no previous mindfulness training.

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[1] This is based on Saunders (2020) teaching of the Buddhist background to mindfulness-based approaches, Centre for Mindfulness Research and Practice, Bangor University, North Wales.

Table 1

Non-exhaustive List of Defining Features of Mindfulness in this study

Definition	**Concepts**	**Attitudes**	**Practices**	**Materials**
The active cultivation of kindly awareness	Mindfulness as present moment awareness	Kabat-Zinn's 7 attitudinal foundations	Body Scan meditation Body Scan w. explicit guidance on pleasant/unpleasant sensation	Mindfulness: finding peace in a frantic world (book and audio recordings; Williams & Penman, 2011)
	Mindfulness as self-care	Gentleness; Kindness; Self-compassion	Sitting meditation	Jon Kabat-Zinn audio recordings (various)
	Mindfulness as stress reduction	Openness; Curiosity; Discovery	3-Step Breathing Space	Audio recordings from CMRP Bangor University (various)
	Mindfulness as mode of mind		Open Awareness with explicit verbal naming of pleasant/unpleasant experience as it arises	In-vivo within session recordings

1.1.2 Buddhist Origins of mindfulness and its place in Buddhist teachings

At the heart of the Buddha's teaching lie "Four Noble" or "Ennobling Truths." The First Noble Truth represents the Buddha's diagnosis, the Second his aetiology for the existence of *dukkha* (a Pāli term often translated as 'suffering'), the Third Noble Truth represents a hopeful prognosis and the Fourth represents a prescription or pathway for the eradication of suffering.

The "Eight-Fold Path" is an elaboration of the Fourth Noble Truth, *'the way leading to the cessation of suffering'*. The "Eight-Fold Path" can be seen as a multifaceted jewel, in which each of its eight parts are reflected in each other. These parts are associated with Wisdom (Right View; Right Intention), Ethics (Right Action; Right Speech, Right Livelihood) and Meditation (Right Effort; Right Mindfulness; Right Concentration). Here mindfulness is positioned as the seventh factor, connecting and balancing the two other aspects of mind – its energetic aspect (Right Effort) with its tranquil, calming aspect (Right Concentration; Bodhi, 2011). Taken together, these eight factors leading to an end to suffering were the Buddha's prescription for realising true freedom and lasting happiness.

Mindfulness and its position on the Eight-Fold Path has been referred to as *"The Heart of Buddhist Meditation*" (Nyanaponika, 2012; Kabat-Zinn, 2013). The term "mindfulness" was first translated from the Pāli word 'sati' by Asian language scholar T.W. Rhys Davids (Bodhi, 2011) and has many possible meanings and interpretations, depending on the context in which the term is used. These include: remembering, recalling, keeping in mind, clear comprehension, watchful awareness, careful awareness, lucid awareness and bare attention (Bodhi, 2011; Dreyfus, 2011). The 'remembering' aspect of mindfulness is a key feature as it appears within the Eight-Fold Path – the Buddhist pathway to awakening (Goldstein, 2013).

One of the Buddha's most compelling teachings that explains the centrality of mindfulness is that of the Sallatha Sutta (Saṃyutta Nikāya 36:6). In it the Buddha differentiates between 'primary' and 'secondary' suffering, using the analogy of two darts or arrows. Primary suffering, such as impermanence, sickness, old age and death are unavoidable. This represents being struck by the first of two arrows. However, according to the Sutta, it is our reactions to these primary sources of inescapable suffering that often compound and makes them even more difficult than they already are. This is avoidable secondary suffering and is likened to being struck by a second arrow – one in which we fire at ourselves. This second arrow is the focus of the Buddha's teaching in this Sutta – the possibility of experiencing freedom from unnecessary, additional suffering. Seen in this context, mindfulness can help to distinguish between primary and secondary suffering and identify ways in which we may inadvertently make difficult experiences even worse.

From this brief overview of where mindfulness sits within Buddhist teaching it is perhaps understandable that some Buddhist scholars have been critical about the secularisation of mindfulness, stripped of its position on the Eight-Fold Path (Purser, 2014; Dreyfus, 2011). However, equally valid arguments have been made (Teasdale & Chaskalson, 2011a; Bodhi, 2011; Kabat-Zinn, 2011) for making mindfulness available in the service of the alleviation of suffering beyond Buddhism. This appears to be highly consistent with the Buddha's original intention in sharing his insights.

1.1.3 The socio-cultural context

As interpretative phenomenology (Smith et al., 2009) and making sense of experience is inherently context dependent, it is important to locate this study in the wider socio-cultural landscape. Kellehear (2007) has traced the social history of dying in the West, culminating in medicine's ability first to control many aspects of biological death and more recently, its timing. Choice in when death occurs in terms of euthanasia and assisted suicide, appears to be a response to what Kellehear (2007) calls the rise of the 'shameful death' in modern times. Several authors have commented on the unintended consequences for medicine as a result of its success in treating disease and extending life (Vanderpool, 2015; Cassell, 1982/2015; Jenkinson, 2015; Solomon et al., 2015). This seems to have led to a situation where people can feel cheated by death, making failure to prevent death, medicine's responsibility. This latter development is particularly interesting from a history of medicine perspective, as the ability to respond to how dying happens has now been extended to when it occurs. In assuming responsibility for the existential given of death, arguably medicine has overstepped its limits.

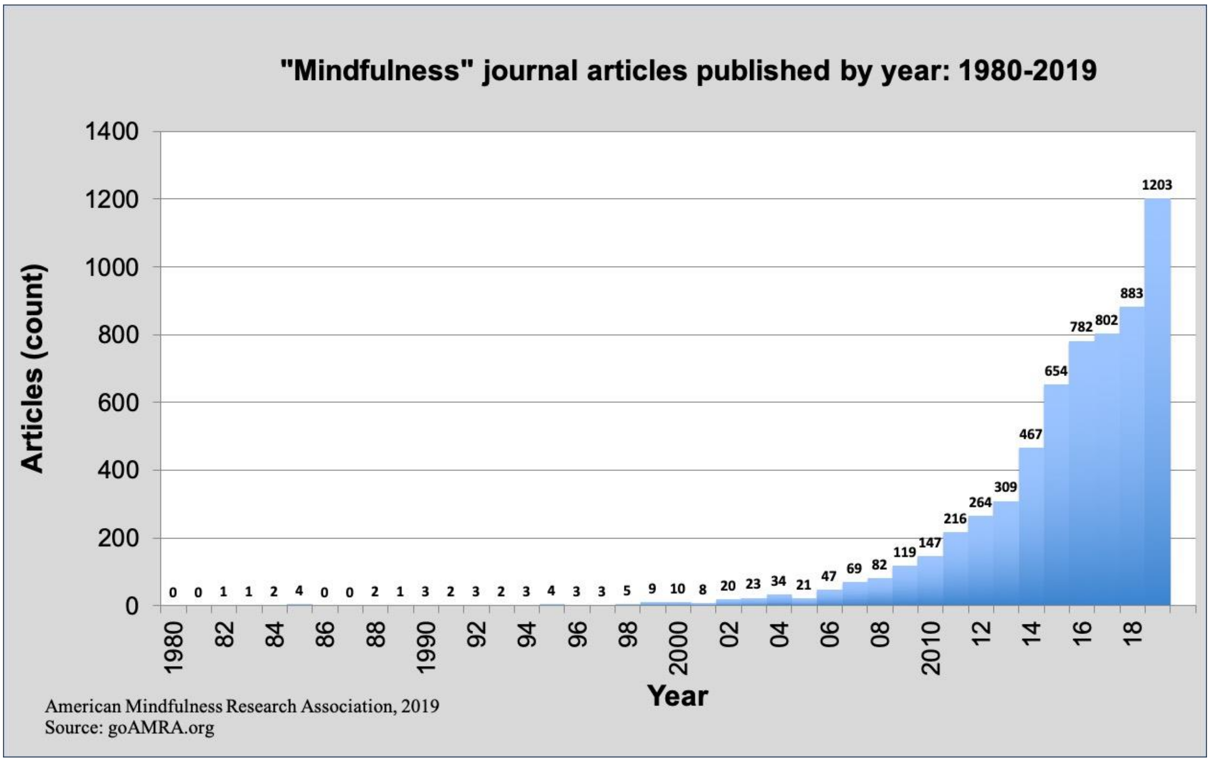
Ernest Becker in his Pulitzer Prize winning 'The Denial of Death' (1997) set out a compelling argument for culture's role in serving a death denying function. Becker argued that culture does this through conferring on its members a sense of self-esteem by playing a valuable role in a meaningful universe. This, Becker claimed, ultimately serves to buffer unconscious death anxiety. Ingenious research by a team of experimental social psychologists researching the effects of Terror Management Theory (TMT; Solomon et al., 2015) lends substantial support for many of Becker's ideas. A study by Neel et al. (2013) demonstrated an inverse relationship between death anxiety and self-esteem in a palliative care sample, lending further support to TMT.

There is now wide recognition that mindfulness has gone ‘mainstream’ by public media sources (e.g. ‘The Mindful Revolution’, TIME Magazine, February 2014; ‘Mindfulness Goes Mainstream’, PBS, 2018). Perhaps somewhat paralleling the growth in popularity of yoga as a way to care for the body, public perception of mindfulness appears to be changing from that of an esoteric practice for the few to a mental health practice for the many (Mental Health Foundation, 2020; Health Service Executive, 2020). As a result, mindfulness is now big business. For example, Forbes magazine valued the mindfulness ‘Headspace’ app’ at $250 million dollars (Chaykowski, 2017). Similarly, the US Military has funded mindfulness training as part of its ‘resilience’ project to the tune of $4.3 million dollars (Purser, 2014).

This change in public mood is fuelled by research from scholars in the fields of neuroscience, cognitive science, psychology and medicine. The fact that mindfulness is on an exponential growth curve is evidenced by the number of peer reviewed papers published with ‘mindfulness’ in the title since the early 1980s. (see Figure 1; source: goAMRA.org)

Figure 1

Mindfulness Journal Articles Published by Year: 1980-2019



As the evidence base, popularity and financing of mindfulness grows, the quality of research and scrutiny studies are subject to, justifiably increases. From early outcome studies based largely on self-reports, to increasing numbers of mixed methods studies employing fMRI and EEG data, the field has responded to the need for more robust data analysis. Criticism about presenting mindfulness as a 'panacea' were never espoused by the mindfulness research community itself but instead came from those rightly sceptical about generalisations made on the basis of a small number of studies. This has prompted researchers to design studies of increasing complexity, employing dismantling designs and active controls (Van Dam et al., 2018; Sauer et al., 2013).

1.1.4 Thesis overview

So far, a background to mindfulness has been provided. An overview and brief history of the specialty of Palliative Care will be offered next, particularly from the context of my professional work in two hospice settings in Dublin, Ireland. A review of psychological distress and the role of psychology will then be presented. The relevance and application to the profession of counselling psychology will also be discussed. Following this, a reflexive statement which aims to capture my own interest in this topic and intention in undertaking this study will be presented. In the penultimate section, a review of the evidence for mindfulness in healthcare will be offered before more critically reviewing studies with patients receiving Palliative Care. The chapter concludes with pointing to a gap in the literature and justifying the approach taken in this thesis.

Chapter Two presents the methodology and begins with outlining my epistemological position and rationale for choosing Interpretative Phenomenology (IPA; Smith et al., 2009) over other qualitative approaches. A background to the chosen methodology is presented, as well as outlining important ethical issues. Two considerations are particularly important here – the negotiation of dual roles of clinician/researcher and the nature of bias. Following this, participant inclusion/exclusion criteria are outlined as well as the method of data collection. The final sections of this chapter present an explanation of the different stages of analysis within IPA and offer a summary of my reflexive research journey.

The analysis itself is set out in Chapter Three. A summary table presents the overall superordinate themes and individual subthemes. Following IPA (Smith et al., 2009) these reflect a process of deep engagement and interpretation of the transcribed individual interviews. Each theme is set out with representative quotes from participant transcripts to allow the Reader to follow my own sense-making of the data. (Examples from the raw data are given in Appendix H).

The concluding chapter re-presents each theme from the analysis, this time setting these within the wider research and clinical context. Implications and possible future directions for research are outlined, as well as acknowledging the strengths and limitations of the current study. A final reflexive piece attempts to capture the research journey as a whole.

1.2 Palliative Care

1.2.1 Definition(s)

The term ‘Palliative Care’ was first chosen for this new medical specialty by Canadian physician, Balfour Mount, who established the first such unit in a teaching hospital in Montreal in 1975 (Saunders, 2000). The World Health Organisation (n.d.) defines palliative care as:

“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (WHO, n.d.; para. 1.)

The European Association for Palliative Care (n.d.) offers its own definition:

“the active, total care of patients whose disease is not responsive to curative treatment. Palliative care takes a holistic approach, addressing physical, psychosocial and spiritual care, including the treatment of pain and other symptoms. Palliative care is interdisciplinary in its approach and encompasses the care of the patient and their family and should be available in any location including hospital, hospice and community. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death and sets out to preserve the best possible quality of life until death.” (EAPC, n.d.; para.2.)

Although this definition of palliative care includes reference to both hospice and community settings, a distinction has emerged over the past decade with regard to the provision of palliative care versus hospice care. In a return to the origins of the modern hospice movement before the development of the specialty of palliative care, hospice care may be increasingly seen as caring for those who are actively dying or in the terminal phase of their illness. Although palliative care is not limited to the care of cancer patients, the National Institute for Health and Clinical Excellence (NICE, 2011) also sees the emotional and spiritual support of advanced cancer patients as a priority. Psychological care of the patient is therefore central to modern definitions of palliative care.

1.2.2 Origins, types and levels of palliative care

The modern hospice movement is widely recognised to have its origins in the pioneering work of Dame Cicely Saunders (Milicevic, 2002; Saunders, 2000) at St. Christopher's Hospice in London in the 1960s. Initially trained in nursing, then social work and finally as a medical doctor, Dame Saunders embodied care of the whole person. The famous motto of St. Christopher's sums up the philosophy of hospice care: "You matter because you are you and you matter until the end of your life. We will do all we can not only to help you die peacefully, but also live until you die."

Although hospice and palliative care were synonymous in the early years of the specialty, a distinction has occurred in recent decades. Palliative care is often introduced early in a person's care, often alongside other disciplines as a subspecialty with expertise in pain and symptom management. Early palliative care involvement has also been linked to greater survival time (Bakitas et al., 2015). This has meant that hospice care has increasingly specialised in caring for patients at the latter stages of their disease and those who are dying. This distinction originated in the United States but has increasingly become part of the European landscape.

In the Republic of Ireland where this study takes place, palliative care is divided into three distinct levels of care (Joint Health Service Executive and Irish Hospice Foundation Report of the Extending Access Study; 2008). This is based on the degree of specialist palliative care provision, which is often associated with where the care is provided. Level 1 recognises that a palliative care approach is a key skill of all clinicians working in both community and hospital settings. Level 2 or intermediary palliative care approach is synonymous with a general palliative care approach where some healthcare providers will have some additional training or experience. Level 3 refers to the provision of specialist palliative care (SPC) by professionals with recognised skills and expertise in delivering palliative care. These services specialise in palliative care and are therefore synonymous with hospice care. This study took place in the context of Level 3 palliative care.[2]

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[2] Further details in relation to the context of this study follow in the Methodology chapter.

1.2.3 Psychological distress in palliative care

The term ‘symptom burden’ (Cleeland & Reyes-Gibby, 2002) denotes the extent to which a person experiences any of the major symptoms associated with their disease. Gapstur (2007; pp.67) has defined symptom burden as “the subjective, quantifiable prevalence, frequency, and severity of symptoms placing a physiologic burden on patients and producing multiple negative, physical, and emotional patient responses.” In a palliative care context these typically include symptoms such as pain, dyspnoea, fatigue, anorexia, emotional distress and nausea. Brief measures such as the Edmonton Symptom Assessment System (ESAS; Bruera et al., 1991) and Palliative Care Outcomes Collaboration (PCOC; University of Wollongong, 2020) are used to assess and prioritise symptom burden in palliative care settings. Understandably, much of the focus in the medical specialty of palliative care is on managing these symptoms as they often severely impact patients’ quality of life. Despite the continuing best efforts of medicine, many of these symptoms remain burdensome for patients. As Eric Cassell (1982/2013/2015) has noted, “bodies do not suffer, persons do” (Pp.62; 2013). It is the patient’s experience of illness that is paramount and which when unacknowledged can be such a major source of suffering. The fact that many patients are also facing a high degree of uncertainty in the context of end-of-life often compounds this burden.

According to the literature, rates of psychological distress in patients facing end-of-life and receiving palliative care are significant. For example, in one meta-analytic study the prevalence rate for all mood disorders was 29% (Mitchell et al., 2011). This rate represents just those experiencing clinical levels of anxiety, depression and/or adjustment disorder – not those who may be experiencing sub-clinical or fluctuating levels of emotional or existential distress. However, rates of distress need to be interpreted cautiously as Block (2006, pp.757) suggests, “few epidemiologic studies of psychiatric disorders in palliative care include broadly representative patient populations, focus on patients with advanced disease and use rigorous evaluation methods, such as structured clinical interviews.” Nor does it represent people with pre-existing mental health conditions or diagnoses such as delirium, personality disorder or psychosis.

The limitations of using standard measures to assess anxiety and depression among palliative care patients becomes immediately apparent when reviewing the criteria to make such a diagnosis. For example, even the most commonly used (Wasteson et al, 2009) assessment tool, the Hospital and Anxiety Depression Scale (HADS; Zigmond & Snaith, 1983) is limited due to some of the items assessing energy and activity level. As Huey et al.

(2018) suggest, better predictors of depressed mood in this cohort are pessimism, dysphoria and loss of interest. Professional experience would also suggest adding perceived burden, level of dependence, hopelessness and suicidality to this list.

The main diagnoses of adjustment disorder with anxiety and/or depression are common responses to receiving a life-threatening diagnosis (Horowitz, 2013; Pessin et al., 2002) and living with ongoing uncertainty around the nature and timing of disease progression. Although these are common responses to confronting mortality and the existential 'givens' (Yalom, 1980/1989) of existence, this may be lost in the predominant focus of the medical model on the palliation of symptoms and treating disease (Cassell, 2015). Psychology may also play a role in normalising what are expected or predictable reactions to advanced illness. Given the socio-cultural context discussed earlier, there is a danger that dying may in itself be viewed as a traumatic event, when it could be argued that our reactions to death and dying culturally are learned phenomena (Jenkinson, 2013; Becker, 1974).

1.2.4 The Multidisciplinary Care Team in palliative care

Just as the patient and family are the unit of care within palliative care, the multidisciplinary care team (MDT) is the provider of that care. The composition of MDTs in palliative care varies widely, often due to available resources. For example, liaison services for some disciplines may be available to palliative care teams located within hospital settings. Disciplines typically represented reflect an overarching intention to offer patients the best possible quality of life and can include medical and nursing teams, physiotherapy, occupational therapy, medical social work, chaplaincy, complementary therapies, dieticians, speech and language therapy and psychology. As the focus within palliative care is primarily excellent symptom control and management, the MDT is usually coordinated through referral from medical and nursing teams. Due to resource availability, some disciplines may be routinely involved in patient assessment and care. Other disciplines may only become involved following specific requests from colleagues within the MDT or from patients themselves. Psychology, where it does exist, is often in this category within the MDT.

1.2.5 Psychology's role in palliative care

Psychology in palliative care is in its infancy (Strada, 2018). The role of psychology and psychological care of the (dying) patient has been largely missing from modern medicine and arguably remains so. As an example of this, in researching the literature on this topic just 26 downloads and 16 citations of Hackett's seminal (1976) paper on "Psychological assistance of the dying patient and his family" were recorded from the journal's website. Fast-forward thirty years and Susan Block's (2006) comprehensive review of "Psychological issues in end-of-life care" was cited just 153 times. These, as well as Strada's (2018) first textbook in the area of *"Palliative Psychology"* all point to the continuing challenge of recognising suffering (beyond its medical management) and establishing psychological care as an area of specialty within palliative care. Why is this? As Cassell (1982/2013) has elucidated, to acknowledge suffering is to be able to recognise it when we encounter it. This involves a certain degree of openness and willingness on the part of health professionals. This may be a hangover of a more paternalistic medicine where things were done to and for the patient rather than in collaboration with the patient.

As one of the more recent additions to the MDT, psychology has much to offer patients, informal caregivers and staff, yet relatively few posts mean that much of its potential remains untapped. There are currently only a handful of psychologists working in palliative care in the Republic of Ireland. Although a growing specialty within the NHS in the UK, the number of full-time positions remains relatively low. Given the nature of medicine and its clinical context, these posts are primarily advertised as Clinical or Counselling Psychology posts. Larger hospital settings with teams or departments of psychology may have access to specialist neuropsychological assessments, particularly where dementia or cognitive deficits due to primary or secondary cancers are suspected.

Over the last decade, attempts to articulate discipline specific competencies within palliative care have been made at both European (Jünger et al., 2010) and latterly at a more local level in Ireland (Palliative Care Competence Framework, Ryan et al., 2014). This has mirrored attempts to classify the different levels of palliative care, outlined in 2.2 above. Although the 'Competence Framework' is the same for all disciplines, encompassing: (i). Principles of Palliative Care; (ii). Communication; (iii). Optimising comfort and quality of life; (iv). Care planning and collaborative practice; (v). Loss, grief and bereavement; (vi). Professional and ethical practice; discipline specific competencies for psychology have been outlined within each of these domains. Strada (2018) has also described the contributions psychology can make to the eight areas of competency that form the U.S. Clinical Practice Guidelines for Quality Palliative Care.

1.2.6 Counselling Psychology's place in palliative care

Counselling psychology is well-placed to make a significant contribution to the alleviation of suffering in patients and families, as well as offering support and training to medical teams and volunteers working in palliative care. The particular skill mix of Counselling Psychologists – self-awareness borne of our own therapeutic work (including existential themes), the ability to listen deeply in the course of psychological assessment, formulation, and counselling – has much to offer in managing the psychological distress associated with end of life. The skills to form safe, effective therapeutic relationships quickly in a context where patients' health status can deteriorate rapidly are part of counselling psychologists 'stock in trade'. This depends on a willingness to remain open and transparent to patients in a context that has many different types of health professional fulfilling different roles. Counselling Psychology can offer patients an opportunity to reflect on and integrate the experience of illness in a way that can hold and offer 'containment' (Finlay, 2016; Casement, 1985) within the ambiguity of uncertainty and not knowing. In a palliative care context, these are often unacknowledged but nonetheless vital skills which can be fostered into the final days of life.

1.3 Reflexive Statement

This research is informed by a twenty-year interest in two topics – firstly, in how individuals navigate the internal journey of dying and secondly, in mindfulness meditation. My interest was initially fuelled by "*The Tibetan Book of Living and Dying"* (Sogyal, 1992) which skilfully combines both of these topics. Ironically, it felt like a weight had been lifted from my shoulders, reading that Buddhist philosophy encouraged living with an awareness of impermanence and dying. It was a relief born of something I instinctively knew but had been unable to articulate. In dying I had ironically found my *raison d'etre*. Death, dying and impermanence were central to living.

These were themes I had been struggling with on and off for many years. For example, from an early age (five or six) I was frequently aware and grief-stricken at the thought of the death of my parents. I was also acutely aware of the deaths of my grandparents and the void their deaths left behind. Later I would learn that I was critically ill as an infant and spent a number of weeks in two hospitals. This was due to a serious infection that was initially unresponsive to treatment. At some (pre-verbal) level, I believe this early encounter with mortality may have sensitised me to themes of death, dying and impermanence. I would later experience night-time 'death terrors' where I come face to face with a raw awareness, not of dying or the dying process *per se* but a sense of total annihilation on dying. It is as if in the mirror of deep dreamless sleep, the ego glimpses its own finitude.

I believe that my choice to study psychology as an undergraduate was (unconsciously) partly motivated to understand how other people make sense of these existential themes. However, it was not until I read Sogyal Rinpoche's (1992) book and especially the foreword by His Holiness (H.H.) the Dalai Lama that I knew where I needed to be. In the foreword H.H. stated that it is certain we will die. However, because it is uncertain how or when we will die, we pretend as if it is never going to happen. This resonated deeply with me and I committed to understanding how Buddhism might be helpful in living with death and impermanence in mind. I think part of the 'weight' that was lifted from me was the confusion or dissonance that although death was certain, death awareness played little role in everyday life. Here for the first time, I encountered a philosophy that not only articulated something deeply meaningful to me but also encouraged me to make it a central feature in living.

As a result of this discovery I sought out and was fortunate to work directly in palliative care as a care assistant, where I attended to the physical care needs of patients receiving palliative care for four years. This time gave me privileged access to patients at end-of-life and the meaningfulness of the work confirmed to me that I was working in the right area. After approximately two years at the hospice, I attempted to secure a place on a graduate-entry medicine programme and latterly, clinical psychology training. However, both of these seemed impossible for me to access. It was not until I became aware of the discipline of Counselling Psychology and its congruence with me as a person, that I finally felt truly aligned in my purpose to ultimately work as a counselling psychologist in palliative care.

Although practicing meditation for approximately five years, it was not until I encountered MBCT (Mindfulness-Based Cognitive Therapy; Segal et al., 2013) that I became aware of mindfulness outside of Buddhism. This was thanks to my hospice placement supervisor on the MSc in Counselling Psychology in 2005, who recommended that I attend a residential training retreat with the Oxford Mindfulness Centre. Ironically, it was this training and secular retreat experience that helped me understand the meditation practice I had been engaged in within a Buddhist context for the previous five years. The fact that my personal practice had now become a *bone fide* evidence-based psychological intervention was an astounding coincidence and confirmation that I was on the right track.

Since qualifying with a M.Sc. in Counselling Psychology in 2007, I have worked in the areas of psycho-oncology and palliative care on and off for ten years. For the last five years I have worked as Senior Counselling Psychologist in the largest hospice/palliative care organisation in Ireland. I was extremely fortunate to have the opportunity to work again with the colleague and supervisor who initially encouraged my interest in pursuing MBCT training. This meant I was in the rare position of having a mentor who was equally enthusiastic about mindfulness with whom to share experiences of using it as a core therapeutic skill. Given the relative infancy of psychology in palliative care, not to mention mindfulness, to have had this kind of support has been truly invaluable.

Prior to taking up the post of Senior Counselling Psychologist in palliative care I was immersed in the teaching and training of mindfulness-based programmes at the Centre for Mindfulness Research and Practice (CMRP) at Bangor University, North Wales. Bangor University established the first Master's programme in mindfulness in the UK in 2002. Professor Mark Williams, one of the founders of MBCT (Mindfulness-Based Cognitive Therapy; Segal et al., 2002/2013), had established much of the groundwork for this before his move to establish the Oxford Mindfulness Centre around the same time. I joined the team at CMRP as Master's Programme Lead from January 2012 until December 2014. This time allowed me to deepen my understanding of mindfulness, primarily through training others to teach. This followed MBCT becoming part of NICE Guidelines in 2011 as the recommended treatment for recurrent depression. Having played a key role in the initial randomised controlled trials of MBCT, the CMRP, along with Exeter University continued to research its subsequent rollout within the National Health Service (NHS). I was therefore among colleagues at the CMRP who were at the forefront of mindfulness' rollout within the NHS. I continue to remain part of CMRP's core training team.

I have worked with many patients both individually and on a group basis in their adaptation to palliative care and end-of-life. Mindfulness has remained a core therapeutic orientation within this work. In the context of palliative care, the focus is no longer on cure. It is on this basis that mindfulness may have much to offer, both on a stress reduction basis, as well as an approach to living with advanced illness. As a way of being present, through the active cultivation of kindly awareness, it may be a source of support until a person's final moments.

This study was undertaken in the spirit of a mindful inquiry – a genuine curiosity to know the potential of mindfulness at end-of-life. As I have invested many years developing my practice and understanding in this area, the potential for confirmation biases (Rosnow, 2002; Rosenthal & Fode, 1963), as well as participant demand characteristics (Orne, 1969) to impact the data in this study was highly likely. This will be more fully outlined in later chapters, particularly as I encountered them during the analysis. Notwithstanding these influences on the data, my intention in this study was to clarify what benefit, if any, mindfulness may offer patients receiving palliative care. Before this study, my view of the potential of mindfulness at end of life was mostly based on a small number of studies and professional experience. The purpose of this research was to hear directly from participants about their experience of mindfulness and make sense of this through IPA (Smith et al., 2009). I hoped that by clarifying my own thinking and understanding of what mindfulness may have to offer, this might serve to advance future research and practice in palliative care.

1.4 Mindfulness in western healthcare settings

Jon Kabat-Zinn (1990/2013; 2011) is a pioneer and visionary in seeing the potential mindfulness meditation could have in western healthcare.[3] From the late 1970s, he and colleagues at the University of Massachusetts Medical Center in the U.S. began teaching (and crucially, researching) an eight-week meditation-based stress education and awareness programme for health. Initially called the 'Stress Reduction Programme' it subsequently came to be known as 'Mindfulness-Based Stress Reduction' or MBSR (Center For Mindfulness, 2017). The programme was developed particularly for people with chronic physical health conditions for whom, as Kabat-Zinn put it, "had fallen through the cracks" of the medical system and who were advised to learn to "live with" whatever medical condition they were facing, without ever being shown how to do this (PBS, 1993). Therefore, MBSR

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[3] It should be noted that around the same time, both Ellen Langer and Marsha Linehan independently began researching and incorporating mindfulness into their work. Langer (1989) at Harvard University, researched the positive effects of living with heightened awareness. For Linehan (1993), mindfulness became part of a multi-component approach to working with people who were suicidal. This programme eventually developed into Dialectical Behaviour Therapy (DBT; Linehan, 1993) for people with a diagnosis of borderline personality disorder.

was a compassionate offering to those who were suffering, with little prospect of cure. The success of MBSR coupled with the notoriety it gained through being featured on Bill Moyers' (Moyers, 1995) "Healing and the Mind" series (Public Broadcasting Series, 1993) led to greater demand and interest in MBSR. This was followed in the late 1990s by a group of researchers tasked with developing an intervention to treat major depressive relapse – a chronic mental health condition. Based on the success of MBSR in alleviating the stresses associated with chronic physical conditions, Zindel Segal, John Teasdale and Mark Williams developed Mindfulness-Based Cognitive Therapy (MBCT; Segal et al., 2002/2013). As seen in 1.3 above, there is now exponentially expanding research literature investigating the effectiveness of both of these approaches in a range of clinical and non-clinical populations and settings.

A number of meta-analytic outcome studies have shown that increased mindfulness was correlated with decreased mood disturbance, reduced stress and increases in self-regulated behaviour and positive emotional states in both clinical and non-clinical populations (Khoury et al., 2015; Chiesa & Serretti, 2009; Grossman et al., 2004). There is also a growing body of evidence that supports the use of mindfulness for people with chronic mental health conditions, such as severe depression and anxiety (Khoury et al., 2013; Segal et al., 2013). A recent overview and systematic review of 23 systematic reviews concluded that mindfulness-based interventions in healthcare were significantly more effective in reducing depression, anxiety, stress, and increasing quality of life and physical functioning than wait-list controls or treatment as usual conditions (Gotink et al., 2015). This review is reflective of the broad interest and wide applicability of mindfulness to many different areas of mental and physical healthcare.

One of the strongest areas of evidence is the application of mindfulness to cancer care. A review study (Shennan et al., 2011) and a number of meta-analyses (Cillessen et al., 2015; Zhang et al., 2015; Piet et al., 2012) have shown Mindfulness-Based Programmes (MBPs) to be effective with adult cancer patients in lowering stress, reducing anxiety and depression and increasing positive mood states.

Although a recent review of mindfulness research revealed that the vast majority (70%) of studies looking at the evidence-based interventions of MBSR or MBCT remained at Stage 1 on the NIH stage model for clinical research (Dimidjian & Segal, 2015), research and theory is developing with regard to explaining the mechanisms of mindfulness i.e. how it works. There is now a wealth of evidence from diverse fields such as neuroscience (Farb et al., 2007; Davidson et al., 2003), cognitive psychology (Vago & Silbersweig, 2012; Teasdale & Chaskalson, 2011b; Segal et al., 2013), psychoneuroimmunology - including immune markers (Davidson et al., 2003), telomere length (Epel et al., 2009), as well as self-reports and outcome studies attesting to the effectiveness of MBSR. One of the first papers (Hölzel et al., 2011) to combine a theory of mechanisms of mindfulness with neuroscientific evidence presented a compelling model of the development of enhanced: i). Body awareness; ii). Attention regulation; iii). Emotion regulation; and iv). Change in self-perspective. Similarly, Vago and Silbersweig (2012) have proposed a model that integrates the neurological effects of mindfulness training associated with changes in i). Self-awareness, ii). Self-regulation and iii). Self-transcendence (S-ART).

Neuroscientific research (Zeidan et al., 2011) has demonstrated that healthy participants experienced reduced pain 'intensity' as well as reduced emotional 'unpleasantness' following brief mindfulness training. Importantly, this was even more pronounced in experienced meditators. In addition to the effects of training attention, the development of increased levels of self-compassion and interconnectedness (Feldman & Kuyken, 2011) may directly address feelings of isolation – a key feature of patients who are suffering (Cassell, 2013). It is perhaps for these reasons that mindfulness initially gained traction in the areas of chronic health and pain conditions.

The intentional cultivation of specific 'attitudinal foundations' of mindfulness (e.g. patience, trust, acceptance; Kabat-Zinn, 2013) might also offer patients a way of being in relation to what they are experiencing that is congruent and responsive to the actuality of their lived experience. Feldman and Kuyken (2019) have described the pivotal role compassion plays, particularly when faced by challenging circumstances or difficulty. As mentioned above, compassion is intrinsic to developing a mindfulness practice.

1.4.1 MBSR

Although revised several times (most recently in 2017) the curriculum of Mindfulness-Based Stress Reduction or MBSR (Center for Mindfulness, 2017) remains largely in its original format. It is also the form in which mindfulness is mostly taught in community and healthcare settings. MBSR was conceived arising from Jon Kabat-Zinn's immersion in both

Buddhist and Hatha Yoga practices. He has written about how the content and format of the eight-week programme came to him “in a ‘vision’ that lasted maybe 10 seconds”, while on retreat with meditation teacher, Christine Feldman (Kabat-Zinn, 2011, p.287). It seems this experience offered Kabat-Zinn a glimpse into what was possible if these practices were made accessible to people who were suffering and would never likely visit a meditation centre or go on retreat.

As a result, MBSR offers intensive training in mindfulness meditation, including mindful movement in the form of Hatha Yoga sequences. This represents the ‘Mindfulness-Based’ part of MBSR. The ‘Stress Reduction’ comes in the invitation to notice the effects of weaving mindfulness into everyday life, both formally (through guided meditation practices) and informally (e.g. bringing mindful awareness to ordinary, everyday activities); as well as learning about stress experientially through brief periods of didactic teaching and informal discussion.

The eight-week MBSR programme is designed to be taught over consecutive weeks in a group format, one day a week for two and a half to three hours per session. There is also a recommended silent ‘day’ of mindfulness practice, normally between sessions six and seven, lasting approximately seven hours. Participants are also asked to set aside up to one hour per day to engage in ‘home practice’ for the duration of the eight weeks.

The programme structure of MBSR can be helpfully viewed as an arc, where the first four weeks (the outward arc) lay the foundation for the second set of four weeks (inward arc). This is somewhat analogous to learning how to use a camera. Ideally one needs a steady, stable platform from which to take good pictures. In the same way, the first four weeks of the programme are intended to create a steady, stable platform of attention from which to be able to view one’s moment by moment experience. This leads to noticing habitual patterns (of thoughts, feelings, physical sensations and behaviours) and gradually gaining greater insight into one’s life, leading ultimately to more skilful choices and action (Weeks 5-8 and beyond).

1.4.2 MBCT

Mindfulness-Based Cognitive Therapy or MBCT (Segal et al., 2013) is largely based on MBSR but is adapted to address major depressive relapse. Its three authors were tasked with identifying and creating a therapeutic programme for a very specific cohort of people – those who had experienced major depression in the past and for whom relapse was highly likely.

Inspired by reports of MBSR's success with chronic pain patients, the authors of MBCT were mainly interested in training those most at risk to spot the triggers that could lead to depressive relapse. MBCT was therefore adapted to target the relapse specific triggers of major depression such as rumination and avoidance. Their initial formulation with this focus in mind was called 'Attention Control Training' (Segal et al., 2013). However, they realised after piloting this programme that attention training alone was not enough.

It was through experiencing more of MBSR themselves that it became clear to the authors that the way in which attention is trained is crucial. Rather than a rigid, overly focused attention on mind wandering, the invitation in MBSR was to simultaneously cultivate qualities of warmth, curiosity and openness within the attending itself (Segal et al., 2013). The effects of internalising such a compassionate stance at the same time as cultivating attention was to prove a turning point in teaching those at risk of depressive relapse. Much as the client internalises the person and attitudes of the therapist in successful counselling and psychotherapy (Rogers, 2004; Duncan et al., 2009) there appears to be a similar process at play in cultivating certain 'attitudinal foundations' in mindfulness (Kabat-Zinn, 2013). In addition, more specific elements designed to address the kinds of thoughts characteristic of depression (which often trigger relapse), as well as anticipating and putting a plan in place for future episodes of low mood are also characteristic of MBCT (Segal et al., 2013).

Initial RCTs on MBCT effectiveness demonstrated reductions in rates of relapse of 50% in those who had experienced at least three previous episodes of major depression in the past (Ma & Teasdale, 2004; Teasdale et al., 2000). Although there was no difference in relapse rates between those randomised to continuing with antidepressant medication and those allocated to tapering or stopping their use of antidepressants following MBCT, this provided further evidence of the robustness of MBCT as an alternative to ongoing medication use (Kuyken et al., 2015). MBCT is now the recommended therapeutic intervention in treating relapsing depression for those who have had three or more previous episodes by the National Institute for Health and Care Excellence (NICE Guidance 1.9.1.8).

1.5 Psychological interventions in Palliative Care

Rates and types of psychological distress in palliative care patients are significant and responses to this distress have been relatively consistent over the past two decades (Strada, 2018; Leo & Mariano, 2009; Chochinov & Breitbart, 2000). However, despite the prevalence of mood disorders and emotional distress, they remain largely under-researched, under-treated and at risk of going unacknowledged. Indeed, psychology itself is a relative newcomer to the multidisciplinary team, if represented at all, in palliative care. Perhaps due to the often-complex nature of pain and symptom burden experienced by many patients in palliative care, the focus on the management of symptoms over and above the person's experience of these symptoms has remained the focus of care.

It is interesting to note that developments in the psychological care of patients have largely come from physicians themselves within the discipline of palliative care (Kübler-Ross, 2008; Cassell, 1982; Kearney, 1996; Chochinov, 2012). This may point to multiple difficulties such as the availability of resources, issues around access and 'gate-keeping', as well as expectations of distress when it comes to working with patients with a high symptom burden, where psychological and emotional distress are often medically managed. This is understandable given the relative absence of psychology and the lack of recognition of suffering within medicine in general (Cassell, 1982/2013/2015). As Cassell (2013) has noted, if we acknowledge suffering exists, then we have a responsibility to prioritise it and give it as much weight as other symptoms.

In 2005, Bultz and Carlson made a compelling case for emotional distress to be recognised as the 'sixth vital sign' in cancer care, along with the traditional five of heart rate, respiration, temperature, blood pressure and pain. This was on foot of the Canadian Strategy for Cancer Control's decision to do so in 2004. This has subsequently led to the widespread adoption of the 'Distress Thermometer' (Bultz & Carlson, 2005) a rapid screen for emotional distress, not only in cancer care but also in palliative care ever since. Indeed, psycho-oncology as a precursor to palliative care and beneficiary of more public attention and funding has been to the fore in developing psychological interventions for cancer patients. Given that palliative care was practically synonymous with end-stage cancer care until the late 1990's, palliative psychology has drawn on models such as Cognitive Therapy (Beck, 1991) that have already been adapted within psycho-oncology for coping with serious and life-threatening disease (Moorey & Greer, 2002; White, 2001).

One of the most researched psychological interventions in palliative care is that of Chochinov et al.'s (2005) 'Dignity Therapy'. This is a structured therapeutic approach that culminates in offering the patient a summary letter outlining their personal history as a legacy document. This approach usually requires a number of sessions and therefore a degree of physical stability and cognitive clarity. A recent review and meta-analysis (Xiao et al., 2019) concluded that while promising, findings remain mixed in terms of the effectiveness of this approach with a pooled cross-cultural sample of cancer patients receiving palliative care. The structured and directive nature of this therapy is somewhat incongruent with Counselling Psychology, though some of the session outlines offer useful reminders of the kinds of themes that may arise when working with people with a life-limiting illness.

A recent review and meta-analysis by Warth et al. (2019) on brief (no more than 4 sessions) psychosocial interventions in palliative care found these to be more effective on measures of quality of life, as well as symptom and existential distress than controls. Typical interventions included were dignity therapy, music therapy, one-off narrative therapy and mindfulness sessions. Given the range of interventions distilled from this review, it seems that different modalities may each have something to offer. This takes on extra significance in a palliative care context, as sensory and cognitive impairment can make talk-based therapies inappropriate. In the only systematic review of the evidence for mindfulness in palliative care, Latorraca et al. (2017) reported on just four RCTs using the Cochrane Risk of Bias (ROB) criteria. Only two of the included studies showed significant difference – one in relation to physical aspects of quality of life in favour of the control group (Mularski et al., 2009) and one in relation to perceived stress for the mindfulness group (Ng et al., 2016). However, Ng et al.'s (2016) study was assessed at being at high risk of bias. The research on mindfulness with patients in palliative care will be further unpacked in the next section.

1.6 Mindfulness with patients in Palliative Care

This literature review was conducted in September 2018 and further updated in July 2020. Search terms used in this review are outlined in Appendix G. Search engines and databases consulted were: PsychLit, PsychInfo, Web of Science, JSTOR, MEDLINE, Google Scholar and Primo. No restrictions were placed on publication in terms of time, place or language of publication.

Only a small number of studies on mindfulness with patients in palliative care have been published (Ng et al., 2020; Look et al. 2020; Gianotti et al., 2019; Ng et al., 2016; Bates, 2016; Bergmark Kudan & Edlund, 2016; Tan et al., 2016; van den Hurk et al., 2015; Tsang et al., 2012; Mularski et al., 2009; Chadwick et al., 2008). Studies have been limited by sample size, a lack of detailed information regarding the amount and type of mindfulness training, as well as information about the experience and training of those offering mindfulness. Where these studies have been conducted by the same research group, these will be presented together.

In a modified form of MBSR, Mularski et al. (2009) offered an eight-week Mindfulness-Based Breathing Programme (MBBP) to men with progressive, moderate to severe lung disease (COPD). This RCT study found no significant differences between experimental and control conditions on either objective or subjective measures. However, as little information was available on home practice or teacher training, this study's findings are limited. Furthermore, this population requires heightened sensitivity when using the breath as an object of attention. Tsang et al. (2012) purportedly carried out an MBSR intervention with a mixed group of palliative care patients, however as this was limited to daily practice with an audio-guided 45-minute Body Scan (BS) meditation, this cannot be deemed MBSR in any meaningful sense (see 1.4.1 above). Although the authors reported a difference between the intervention group and controls on measures of pain and emotional health, the relatively small participant numbers as well as the authors' interpretation of MBSR, limit this study's findings.

In a pilot study, Tan et al. (2016) researched the effects of a '5-minute' mindfulness of breathing (MB) training on patients and family members' reports of emotional distress using the 'Distress Thermometer' (National Comprehensive Cancer Network, 2003). They found a significant reduction in self-reports of distress between active and control groups immediately after engaging in MB. In a follow up randomised controlled trial, Ng et al. (2018) reported on the effects of MB on emotional distress and measures of physiological responses in patients only. This study, incorporating subjective and objective measures, found significant differences between the intervention group (MB) and controls on every measure. These included measures of blood pressure, pulse and breath rates, galvanic skin response and skin surface temperature. Although promising, this kind of once-off intervention may simply be experienced as a variant form of relaxation training (Benson, 1975). Given the brevity of the mindfulness training component, lack of didactic input and process of 'mindful inquiry' (Crane et al., 2015) into the development of mindfulness, again this study can only loosely be thought of as mindfulness training.

More recently, the same research group (Ng et al., 2020; Look et al. 2020) reported on the effectiveness of a single session of 20-minute MB practice with patients admitted for heart failure (Ng et al., 2020) as well as any adult palliative care patient scoring ≥5/10 on the Edmonton Symptom Assessment Scale (ESAS; Bruera et al., 1991) and who had consented to inclusion (Look et al., 2020). Although providing further evidence for the role of complementary approaches with distressed patients in an acute hospital setting, it is unclear what aspect(s) of the experimental condition were responsible for the reductions in dyspnoea found. Furthermore, claims of the effectiveness of mindfulness after single, brief interventions raise more questions around mechanisms of mindfulness, particularly in light of more sophisticated models that currently attempt to do so (e.g., Vago & Silbersweig, 2012). A simple reduction in distress fails to capture the intricate internal processing that is proposed by some authors (e.g., Teasdale & Chaskalson, 2011a; Segal et al., 2013) to explain these changes. As other authors have argued (e.g., Desbordes et al., 2014) the field would benefit from shifting from research on outcomes and efficacy to more nuanced and subtle approaches that might point to what is happening for the person internally. For example, does rumination and catastrophic thinking in relation to shortness of breath decrease following a MB exercise?

Van den Hurk et al. (2015) conducted a pilot study on the effects of MBSR with a sample of lung cancer patients and their informal caregivers. Primary lung cancer generally has a very poor prognosis and the majority of patients in this study had advanced disease. Although no significant difference was found in terms of distress pre/post intervention, informal caregivers reported significantly less burden. Qualitative analysis however indicated that the programme had instigated a process of change in terms of greater awareness of thoughts, feelings and physical sensations. Although under-powered due to sample size and lack of qualitative data saturation, the authors' conclusions reflected the subtlety of what they had observed. Namely, that qualitative data pointed towards the likely future benefit in navigating the final stages of the disease and with greater awareness of (anticipatory) grief. Although the researchers in this study did not employ IPA as a qualitative methodology, this study underscores the importance of qualitative and mixed methods in tracking participant's internal processes.

In a recent Italian study of 20 advanced cancer patients (Gianotti et al., 2019) receiving early palliative care, measures of mood disturbance (POMS; McNair et al., 1971) and self-reports of pain (ESAS) were analysed. Although no significant change was found on ESAS pain scores after the intervention, significant differences were found on pre/post session mood scores. In addition, patient satisfaction was rated at 78% and home practice compliance (participants were asked to practice 45 minutes per day) was 70%. Single outcome measures of constructs as complex as pain are arguably crude measures when it comes to the subtlety of navigating the effects of advanced disease. Indeed, measures of mood disturbance may well offer a better picture of patients' ability to live with symptoms, such as pain. However, a rich vein of data regarding participants' experience is missed when no qualitative component is employed.

Three studies have reported on patients' actual experience of engaging in mindfulness practice (Bates, 2016; Bergmark Kudan & Edlund, 2016; Chadwick et al., 2008). Bates' (2016) study analysed patients' experience of mindfulness practice while engaged in a process of 'mindful inquiry' (Crane et al., 2015) using a Grounded Theory approach (Glaser & Strauss, 1967). Analysis of the 'inquiry' attempts to understand participants' experience of engaging in formal mindfulness practice and could therefore be seen to anchor participant-teacher dialogue close to the actual practice of mindfulness itself. Bates' (2016) discovery that patient's narrative changes from one that is closely bound to the personal story of illness to one that is much more present-moment-oriented, offered a helpful insight into the potential role for mindfulness in Palliative Care.

Bergmark Kudan and Edlund (2016) used a mixed methods, case study approach to look at the impact of seven days of mindfulness training on symptom burden with six patients new to mindfulness. The experience of relaxation was reported as a main shared outcome, as well as pre/post lowering of symptoms on the ESAS. The fact that this study sought to correlate mindfulness training with symptom burden was an innovative approach and one the present study proposed to pursue further in the semi-structured interview. However, as this study did not employ IPA and was published only in the Swedish language, this has unfortunately limited its impact in the research literature.

Chadwick et al. (2008) did employ an IPA approach with four patients with advanced cancer. All four patients attended a 6-week, one hour per week group mindfulness training. This comprised of two 10-minute guided MB sessions, followed by group discussion. Seven themes were identified, including benefits of mindfulness, the hospice context, as well as the supportive role of the group. As this was relatively low intensity mindfulness training (compared to the current study) offered on a group basis in a hospice setting, it is interesting to note the themes reflected these factors. Also, as themes were generated by open-ended discussion, effects of the practice in relation to specific aspects of illness such as symptom burden went unexplored. The present study was specifically designed to explore these themes, as well as to ensure greater intensity and exposure to mindfulness.

1.6.1 The case for a tailored mindfulness programme in palliative care

Unsurprisingly, MBSR and MBCT's success has led to interest in the wider application of MBPs to different areas of mental and physical healthcare. Crane, Brewer, Feldman, Kabat-Zinn, Santorelli, Williams and Kuyken (2017) – all leaders in the field of mindfulness research and practice – presented what they see as the defining features of mindfulness-based programmes. Drawing an analogy with the 'warp' (vertically similar, fixed threads) and 'weft' (individually coloured horizontal, textured threads) in weaving, they outlined programme and teacher elements that are shared across all mindfulness-based programmes (the warp), whereas other features are specifically tailored to fit the particular context and population of interest (the weft).

Taking Crane et al.'s (2017) 'warp and weft' paper as a framework, the 'weft' elements of this programme included short (30 minutes as opposed to 150 minutes), individual (as opposed to group) sessions, personally tailored (in response to the person's individual symptom burden e.g. breathlessness, fatigue, anxiety) and brief practice periods (3-15 minutes as opposed to 45 minutes). In terms of content, the focus was on experiencing the effects of stabilising attention by emphasising the focused attention practices of the body scan and mindfulness of the breath and body. Sessions were largely based on the MBCT-derived programme outlined in *'Mindfulness: A practical guide to finding peace in a frantic world'* (Williams & Penman, 2011). This offered a structured approach based on widely available supportive materials (printed book, audiobook and web application-based formats).

There is a strong rationale in the context of palliative care for emphasising focused attention mindfulness practices (particularly those associated with Weeks 1-4 of MBPs). The ability to find some 'stability' (Cooper, 2016) in the context of high levels of uncertainty surrounding prognosis, treatment regimens and fluctuating symptom burden, through focusing on a reliable, accessible object or ‘anchor’ of attention has also been highlighted as a key mechanism of mindfulness (Hölzel et al., 2011). [More specific details relating to tailored elements of individual sessions in this study are outlined in Appendix A]

Other aspects of mindfulness, such as the relevance of noticing ‘mind wandering’ and choosing to bring attention back to the present moment, may also have much to offer those receiving palliative care. For example, mindfulness does not engage in the ‘story’ or narrative of suffering (Bates, 2016). Instead, it invites a person into a different relationship to experience, one that is intimately connected and responsive to the present moment. Furthermore, as this is a practice that doesn’t rely on speech, it may be especially useful in a palliative care context where certain illnesses can make speech difficult or limited.

Mindfulness involves the intentional cultivation of kindly awareness and offers a way of staying present to whatever is happening, for better or worse, with kindness. It therefore offers a reliability that does not require solutions to be found. There is also potentially a deeper parallel at play here. This is in terms of ‘dying’ or ‘letting go’ of both past and future. This stance encourages being fully awake and alive to the preciousness of the present moment. Kabat-Zinn (1993, 33:30) puts it like this: “…the only time any of us have to grow, to change, or feel anything or learn anything is in the present moment.”

1.7 The aim of this research

As presented above, few studies have looked at the role of mindfulness with palliative care patients. Where they have, the majority have looked at patient reported outcomes or have attempted to develop a theoretical model as mindfulness experience develops. Furthermore, all except Bates’ (2016) study were conducted with patients who were relatively new to mindfulness. The aim of this dissertation was in some ways more basic. While recognising and allowing for personal bias, the aim of this study was to understand the effects of a well-established mindfulness practice and what it can offer participants as they navigate serious illness, particularly in relation to symptom burden. When are patients more likely to engage in mindfulness practice? What benefit might it offer? Would they recommend it to others receiving palliative care?

It was hoped that participants in this study could help to illuminate the potential for mindfulness in palliative care, including its limitations. For example, to discover whether mindfulness has a role in managing symptoms that can often be so burdensome? Although limited in the number of patients who could be included due to the context and inclusion criteria, it was hoped that this study could reveal important aspects of offering mindfulness practices to patients receiving palliative care.

As mindfulness continues to enter public discourse through mindfulness in schools programmes such as ‘Dot Be’™ and ‘Paws Be’™, as well as popular mindfulness ‘app’s’ such as ‘HEADSPACE’™ people will increasingly have some understanding of mindfulness before they become seriously ill. Therefore, an over-arching intention behind this study was to seek to pre-empt this shift in society to understand the role of a well-established mindfulness practice while receiving palliative care. As the psychology around end-of-life develops and matures, mindfulness may have a role in supporting people to ‘heal’ as per Kabat-Zinn, i.e., to come to terms with things as they are, as well as to adjust to the natural processes around death and dying.

2. Methodology

2.1 Quantitative and qualitative research methods in psychology

Creswell (2014) has outlined three major approaches to psychological research – qualitative, quantitative and mixed methods. Importantly, the philosophical assumptions associated with each broad approach aid understanding and choice of research design. The choice of research method in psychology often follows naturally from the careful refinement of research question i.e., what the research hopes to answer or explore. The number of research participants will then often be determined by the method that 'best fits' the question at hand. For example, questions about general population characteristics are often best approached by randomly selecting a sample from the larger population. This often entails large numbers of participants and making comparisons against pre-determined statistical norms. This has traditionally been the domain of quantitative research in psychology and the 'gold-standard' of randomised controlled trials.

Since the turn of the new millennium, the dominance of quantitative research methods in psychology has been challenged by a re-valuing of individual experience. Increasingly sophisticated and complex research methods have developed to capture the importance of individual experience and from there, gain a deeper understanding of the phenomenon in question. This is the domain of qualitative research in psychology, and it has seen strong growth and interest in recent decades.

2.2 Ontological and epistemological position

Braun and Clarke (2013) see both ontology and epistemology as fundamental in framing any research question. Aliyu et al. (2015) include an understanding of axiology[4] as central to understanding the architecture of research design. Creswell (2014) also emphasises knowing the intersectionality between one's philosophical worldview, research design and choice of research method. Ideally one's philosophical (ontological) position should inform

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[4] Although this section focuses on ontology and epistemology, Aliyu et al. (2015) helpfully describe 'axiology' in research as how one acts (methodology), on the basis of how one views reality (ontology) and makes sense of the world (epistemology).

one’s epistemological stance (i.e., what is considered valuable knowledge), which in turn will influence research design and method.

Ontology is concerned with some of the major assumptions that are often left implicit in everyday discourse. Questions in relation to the world, the nature of existence, of being and reality can all be subsumed into one’s ontological position. When conducting research, it can be especially helpful to clarify the nature of these assumptions about the world, as this directly influences the choices we make about the multitude of research methods at our disposal. For example, a realist stance reflects assumptions that the world is knowable and observable, mainly through use of the scientific method. Therefore, anything that falls within the realm of empiricism is worthy of study and by default, anything outside of this is conjecture. Taken to the extreme, this alternative view of reality is ‘constructed’ by the Knower in the act of knowing and is therefore experienced differently by each individual. This stance reflects the ‘constructionist’ or ‘interpretist’ position (Marsh & Furlong, 2010).

Epistemology or the study of knowledge, encourages us to ask questions such as what ‘counts’ as knowledge, how we ‘know’ what we know, and the assumptions and validity of certain approaches to gaining knowledge. As Braun and Clarke (2013) outline, on one end of a continuum sits the ‘realist’ position, whereby an objective ‘real’ world sits behind all human constructions of it. On the other end sits the ‘relativist’ position which sees all knowledge as ‘relative’ to the position of the Knower. The extreme relativist position therefore does not believe in an objective reality but rather sees all knowledge as influenced by factors such as context, social, cultural and language practices. Between these two extremes sits the compromise position of the ‘critical realist’ perspective. This perspective acknowledges the limits of sensory knowledge and the complexity of attempting to explain events outside of experimental conditions, including the causes and conditions that give rise to events (Hood, 2015). While retaining a belief in an objective external reality, the critical realist position acknowledges the perspective of the Knower in shaping that reality.

The critical realist perspective resonates strongly with my own experience of the world – both as objectively knowable on the one hand yet mediated through the senses and filtered through experience and memory. Critical realism is also highly consistent with a Counselling Psychology approach in terms of developing therapeutic interventions based on identifiable patterns of human behaviour (e.g., the role of rumination and avoidance), as well as the importance of empathic attunement to a client's lived experience and recognising that this will inevitably be different for each person.

2.3 Research design and rationale

Qualitative approaches to research are essentially concerned with meaning (Braun & Clarke, 2013). Qualitative research attempts to understand the essence of a psychological, social, and/or cultural phenomenon primarily through employing the most appropriate research framework for the question or issue at hand. As the focus of this study was the 'lived experience' of palliative care patients of mindfulness practice, the qualitative methodology of interpretative phenomenological analysis (Smith et al., 2009) was chosen.

This idiographic approach is based not on the generation of new theory, but rather on a psychologically informed understanding of each participant's phenomenological world (Larkin et al., 2006). This choice is also consistent with Yardley's (2000) criterion of 'transparency and coherence' between research question, method and analysis when assessing the quality of qualitative research. Furthermore, this study presented an exciting opportunity to allow participant training in and experience of formal mindfulness practice itself to inform the quality of data gathered. Smith et al. (2009) foresaw this possibility,

> "And we will be interested to discover whether the use of various experiential and mindful methods to 'train' or prompt participants to provide a different level of recall – a 're-imagining' or 're-living' or focusing of their experiences – will lead to a strand of IPA work which gets even more 'experience-close'." (Pp. 204)

Formal training in mindfulness practice may be particularly well placed to access this level of experience.

2.4 Interpretative Phenomenological Analysis (IPA)

2.4.1 Phenomenology within IPA

Interpretative Phenomenological Analysis (IPA; Smith et al., 2009) employs in-depth analysis of multiple single cases to offer an insight into how participants experience their world. This draws extensively on the work of German philosophers such as Franz Georg Gadamer, Martin Heidegger and Edmund Husserl, as well as French philosophers, Maurice Merleau-Ponty and Jean Paul Sartre (Smith et al., 2009). Husserl's phenomenological approach to 'return to the thing itself' is a reminder to stay close to the experiential world of the experiencer if we are to understand a given phenomenon (Smith et al., 2009). Heidegger and Merleau-Ponty's insights into the importance of context and time within which an experience is taking place, also offers helpful advice if we are to better understand a person's experience (Smith et al., 2009). This is Heidegger's famous 'dasein' which can be translated as 'being there'. Being is always located in a specific time and location, therefore context is essential to understanding experience. Learning mindfulness in the context of receiving palliative care is clearly different to learning it as part of a community or workplace wellbeing programme. Both of these factors were likely to strongly influence participant engagement in the context of receiving palliative care.

2.4.2 Hermeneutics within IPA

The research method of IPA serves as a basis to engage in a critical and interpretative commentary that takes more contextual and theoretical factors into account in making sense of the data. This is the 'double hermeneutic' (Smith et al., 2009) where the researcher is engaged in an act of making sense or interpreting the experiences reported by research participants. Therefore, the researcher is not only concerned with reporting what research participants say but also analyses and interrogates what is said to reveal a different order of meaning (Larkin et al., 2006).

2.4.3 IPA compatibility with Counselling Psychology

The ethical, idiographic, and meaning-centred approach of IPA is very much aligned with the practice of counselling psychology. Both approaches are continuously informing the literature in a circular, evidence-based process. The centrality of meaning-making in a spirit of discovery and inquiry are also shared by both approaches. Where the two approaches diverge is in terms of their teleology. IPA is concerned simply with understanding and making sense of experience through the ‘double hermeneutic’ as mentioned above. Counselling Psychology seeks to work collaboratively with clients in working towards whatever goal the client may have for therapy, which often includes but can go beyond sense-making.

2.4.4 IPA compatibility with mindfulness

As mentioned in 2.3 there is potentially a rich area of overlap and synergy between IPA as a research method and mindfulness as a mode of inquiry. The qualities of awareness that are central to cultivating mindfulness as both a practice/ process (the directing of attention to the present-moment) and mindfulness as outcome/ state of awareness are highly consistent with a mode of inquiry that is central to IPA (Smith et al., 2009). As such, participants in this study were invited to engage in a brief period of formal mindfulness practice at the beginning of the semi-structured interview process (Appendix A). Pauses were also welcomed by the researcher during the interview itself, as experience of mindfulness can often be difficult to articulate. This shared understanding and experience of mindfulness underpinning participant interviews may have allowed a depth of insight and articulation of experience to emerge that may be missed through more casual conversation. As a methodology, IPA also shares with mindfulness a willingness and trust in allowing whatever is noticed or ‘seen’ from engaging in the process to arise. This ‘letting go’ of any specific expectations (while recognising that there is still a goal to be reached) is an aspect of mindfulness that has contributed to its being called a ‘paradoxical’ approach (Shapiro et al., 2018).

2.5 Consideration of alternative qualitative methodologies

Braun and Clarke (2013) have admitted to 'naming and claiming' Thematic Analysis (TA) as a 'bone fide' method within psychology, based on the work of physicist and science historian Gerald Holton (Pp. 178). This named method subsumes generic qualitative research skills such as identifying, analysing and presenting 'themes' from a given dataset and is a recommended approach for those unfamiliar or new to qualitative methods. Devoid of an ontological or epistemological base, this method offers flexibility in its application to any qualitative research question. However, due to the desire to go beyond mere description to a level of interpretation based on a more defined philosophy and epistemology, this approach was not considered suitable.

Narrative Analysis (NA) places the primary focus on the 'story' itself, both in terms of the content of what is said and how something is said (Smith, 2013). However, unlike TA and IPA, the story or narrative is taken as a whole and does not undergo a theme-by-theme analysis. As the primary unit of analysis is the story itself, this is taken to reflect certain socio-cultural norms of framing or representing experience. As the primary focus in this research is a psychological interpretation of the participant's 'lived experience' and not the socio-cultural narrative surrounding mindfulness or palliative care, this method while offering an interesting perspective, was also rejected.

Discourse Analysis (DA) as defined by Braun and Clarke (2013) was considered on the basis of its utility in understanding patterns of meaning. As the primary focus in this study was not on gaining a socio-linguistic understanding of meaning produced by discourse but rather on making sense of how individuals understood their experience from a more internal perspective, again IPA was favoured. Also, the theoretical and philosophical underpinnings of IPA gave it an advantage, as well as offering a more defined approach to its method.

As the primary motivation for this study was to understand the lived experience of participants a Grounded Theory (GT) approach was only briefly considered. The goal of GT is to develop a theory that might point towards the sociological underpinnings of such experience. Indeed, Braun and Clarke (2013) point towards this in their recommendation to use GT if the research is attempting to understand 'influencing factors' and 'social processes' associated with a given phenomenon of interest (Pp. 186). As the focus in this study was the experience itself and not the socio-cultural factors that gave rise to it, this again confirmed IPA as the methodology of choice.

2.6 Ethical considerations

The British Psychological Society's 'Code of Ethics and Conduct' (2018) and the Society's 'Code of Human Research Ethics' (2014) and the 'principles' therein; i. Respect for the autonomy, privacy and dignity of individuals and communities; ii. Scientific integrity; iii. Social responsibility; and iv. Maximising benefit and minimising harm) were adhered to at all stages of the study. As this study was conducted in the Republic of Ireland, the Psychological Society of Ireland's 'Code of Professional Ethics' (2019) and guiding principles of i). Respect for the rights and dignity of the person; ii). Competence; iii). Responsibility; and iv). Integrity underpinned the interactions and decision-making in this research. Also, as the Professional Doctorate in Counselling Psychology is an approved programme of study with the Health Care Professions Council (HCPC), there is also a requirement to adhere to the ten 'standards' as set out in the HCPC's "Standards of conduct, performance and ethics". As the proposed study was with a vulnerable clinical population in a clinical setting, ethical approval was sought separately from the appropriate governing clinical and academic institutions (see 2.6.1 below).

The psychological well-being of participants was a priority at all stages of the research. As participants were receiving on-going palliative care services, psychological care was in place for all, regardless of inclusion or withdrawal. This is in-line with NICE's (2011) Quality Standard 13 on 'end-of-life care for adults' guidelines. Mindfulness was offered as a core psychological intervention by the two psychologists working as part of the multidisciplinary teams in this context. As such, mindfulness was offered to support participants' psychological well-being. If participants experienced an adverse reaction to the practice of mindfulness, their on-going psychological care would always be prioritised over completion of the programme. The psychologists working in the service frequently explored patients' ongoing experience of mindfulness and participants were free to switch therapeutic modality at any stage. Regular sessions allowed for on-going review and assessment of participants psychological well-being.

2.6.1 Ethical approval

As the proposed study took place within the context of two hospice sites providing multidisciplinary palliative care to a vulnerable population, both academic and clinical research ethical approval was sought.

Academic approval was sought and granted from the School of Psychology at London Metropolitan University (Appendix B). Clinical research ethical approval was received by the research ethics committee at St. Vincent's University Hospital (SVUH), Dublin (Appendix C). This is the governing clinical research ethics committee for Our Lady's Hospice and Care Services and has oversight for ensuring the safety of clinical research participants. The process of gaining clinical research ethical approval involved the completion of the SVUH clinical research ethics approval form, followed by attendance at the clinical research ethics committee's monthly meeting.

2.6.2 Confidentiality and anonymity

As mentioned in Smith et al. (2009) due to the nature of IPA studies, anonymity was ensured but not confidentiality. This is because participant transcripts were transcribed and discussed by different members of the research team (e.g., co-researcher and supervisor). Audio transcripts revealing any identifying information were redacted. Transcripts of sessions were held safely and securely in a password protected laptop computer with encrypted files. These were held in line with the service's data protection and retention policy. Audio files were deleted following the analysis.

2.6.3 Informed consent

Participants meeting inclusion criteria received general verbal information about the study from their treating psychologist and asked if they would be interested in participating. If interested, participants were given the Patient Information Leaflet (Appendix D) and a Consent Form (Appendix E) at their next meeting. On receiving this written information about the study, participants were invited to consider their decision regarding inclusion before being contacted by the 'researcher' (who was another psychologist working in the service) in 48-72 hours. Participants were made aware of the nature of the relationship between their treating psychologist and the psychologist in the role of ‘interviewer’ to aid transparency. This telephone call from the psychologist in the role of ‘interviewer’ (not their treating psychologist) allowed for participants to hear more about the study (e.g., confidentiality and privacy), to ask any questions they might have, as well as to provide their informed consent for inclusion in the study. Arrangements were then made as to the location of the research interview (usually the participant’s home).

2.6.4 Debriefing

All participants were debriefed by the psychologist in the role of ‘researcher’ immediately after the semi-structured interview. They were also offered a follow-up telephone call to discuss any issues that may have been raised by the interview process. Participants also had an opportunity to discuss their experience of being interviewed for the study with their treating psychologist in their next follow-up session.

2.6.5 Dual role of clinician-researcher

The psychology service where this research took place was comprised of two psychologists (one clinical, one counselling). As one of the psychologists was the main researcher, it was vital from the perspective of holding ‘dual roles’ that neither psychologist acted as interviewer with participants who they had been working with in a professional capacity. This separation of roles of ‘interviewer’ and treating psychologist was important ethically for a number of reasons. These included preserving the integrity of the therapeutic relationship, the minimisation of placing demand characteristics (Rosnow, 2002; Orne, 1969) on participants, as well as providing reassurance that a decision not to participate would not impact their ongoing psychological care in any way. In order to achieve this, the two psychologists held separate roles with individual participants, i.e., acted as researcher only or as psychologist/mindfulness teacher only. Overall, this seems to have been an effective means of recruitment and division of roles, as one participant who had received both the PIL and Consent Form, subsequently declined to participate having initially provided verbal consent. Separate professional and research supervision, as well as both clinical and academic research ethics processes, provided external checks with regarding to navigating this dual role as consciously and sensitively as possible. However, the holding of dual roles as main researcher and psychologist was not ideal and will be explored further in the section on methodological reflexivity (2.9.3), as well as in the Discussion.

2.6.6 Researcher declaration

This study took place in a specialist multidisciplinary palliative care service staffed by specialist medical and allied health professionals. The researcher’s interest in both mindfulness and palliative care has already been acknowledged. However, a genuine curiosity to understand participants’ experience, as well as regular research supervision and reflexivity informed a healthy scepticism to counterbalance any bias that may have undermined the quality of data collection or reporting. The researcher acknowledges no outside influence or conflicts of interest.

2.7 Participants

Within IPA studies, a small homogeneous sample is considered a useful starting point to make inferences about similarities and differences amongst the sample (Smith et al., 2009). In this study, recruitment was proposed to finish once 6 patients consented to participate. Purposive sampling (Creswell, 2013) was used to recruit palliative care patients with advanced disease and a prognosis of greater than three months. Prospective participants were identified on the basis of inclusion/exclusion criteria (see 2.7.3 below). Where participants were new to mindfulness, regular individualised sessions over a minimum time period of six months ensured they received extensive mindfulness training.

2.7.1 Recruitment strategy

As this study was attempting to recruit participants with a minimum of six months experience of mindfulness, recruitment took place once suitable participants met inclusion criteria. As participants had been referred for psychological support this could also be considered “opportunistic sampling” (Smith et al., 2009; Pp. 49), as it takes place within the day-to-day work of the multidisciplinary team where a need for psychological assessment and treatment had been identified and referral for psychological assessment made. Both hospice locations provide a range of palliative care services including inpatient beds, community palliative care (home care), and Day Hospice services.

2.7.2 Recruitment challenges

Due to the nature of the patient population only a limited number of participants were able to meet inclusion criteria. For example, the fact that certain disease types can progress quickly after a period of stability, meant that not all potential participants could be included. This happened in one instance in this study. In practice, this required a continual weighing up of diagnosis with prognosis and likely end-of-life trajectory before recruitment was made. Once recruited, participants were free to withdraw at any stage. This also happened in one instance. Generally, once consent had been given, interviews were conducted within the next two weeks due to the probability of future disease progression and decline.

2.7.3 Inclusion and exclusion criteria

Inclusion criteria were established on the basis of any participants who had:

a. Developed a regular mindfulness practice over a period of at least six months either prior to referral or following referral to palliative care.
b. A life expectancy of at least 3 months following recruitment *to the study* (not to palliative care).

Criterion a. was established to ensure that participants had good familiarity with mindfulness in the context of receiving palliative care. Criterion b. was established to ensure participants had a life expectancy that would: (i). allow them to consider their participation, (ii). the interview to be arranged and (iii). allow time for debriefing following the research interview.

A mindfulness practice period of six months was considered important to allow for repeated experiences of practicing mindfulness in the context of advanced illness. (Individual participant mindfulness practice experience is detailed in Appendix A). Although there is currently no consensus regarding what constitutes an adequate mindfulness ‘dose’ (Creswell, 2017; Carmody & Baer, 2009), this time period meant participants were not new to mindfulness.

Exclusion criteria of severe anxiety or depression (based on a score of 15 or greater on either subscale of the Hospital Anxiety and Depression Scale; Zigmond & Snaith, 2000), cognitive impairment (based on a score of 10 or greater on the Short Orientation Memory Concentration Test; Katzman, 1983), psychosis (based on Diagnostic and Statistical Manual-V features) and a life-expectancy of less than three months were also established. (This did not affect patients' access to psychological support). The exclusion criteria listed above reflect conditions in which a participant's attentional capacity may be limited, or in which the intentional cultivation of attention might be experienced as overly burdensome. Along with the cultivation of important 'attitudinal qualities' of mindfulness (Kabat-Zinn, 2013), mindfulness training requires the intentional 'alerting' and 'orienting' of attention over time. This requires a level of awareness that is not overly burdened by competing thoughts, feelings and physical sensations. Without a stability of consciousness participants would unlikely be able to develop a mindfulness practice.

Patients that met the inclusion criteria were offered written and verbal information about the study and followed up by the psychologist they did not know, in the role of 'researcher/interviewer'. Refusal to participate or withdrawal from the study did not affect their ongoing psychological care. Recruitment took place through referral to the psychology service from the multidisciplinary palliative care teams in two hospices located on the south side of Dublin. Given that mindfulness represented the main therapeutic approach taken with these participants, in an overall context of psychological care, close monitoring of the impact of the intervention was assured.

2.7.4 Participant demographics

Three males and one female participant gave informed consent to participate in this study. Their demographic information is set out in Table 3 (below). The demographic information follows Van Dam et al.'s (2018) guidelines in offering transparency around participant background information. All names are pseudonyms but are reflective of gender. All of the participants met the inclusion criteria and had been referred for psychological assessment and support at least six months prior to recruitment.

Table 2

Participant Demographics and Mindfulness Practice Experience

Name	John	Tim	Conor	Claire
Gender	M	M	M	F
Age	50-55	50-55	45-50	55-60
Diagnosis	Rare tumour of spinal cord	Advanced Prostate Cancer	Brain Cancer	Advanced Breast Cancer
Experience of mindfulness prior to psychology referral	No	No	Yes	Yes
Duration of mindfulness practice	1 year	9 months	6 years	20 years
Original mindfulness learning format	Individualised programme*	Individualised programme*	8-week MBSR	8-week MBSR
Retreat experience	No	No	Yes	Yes
Number of individual psychology sessions	26 over 12 months	22 over 9 months	9 over 4 months	6 over 6 months

*The individually tailored programme was based on the book, ‘Mindfulness: a practical guide to finding peace in a frantic world’ (Williams & Penman, 2011); which itself is closely modelled on the MBCT programme (Segal, Williams & Teasdale, 2002/2013). Further details on individual specific mindfulness training practices are given in Appendix A.

2.8 Data collection: semi-structured interviews

Data was obtained by conducting semi-structured individual interviews. This approach to data collection is well-recognised when following an IPA approach (Smith et al., 2009; McLeod, 2011; Braun & Clarke, 2013). Individual interviews are especially useful as they offer a flexible, accessible method of collecting rich data about personal experiences and perspectives (Braun & Clarke, 2013). Further to Smith et al.'s (2009) encouragement to employ more "mindful methods" to get even more "experience close" (Pp.204), the data collection process itself was approached as a mindful dialogue between researcher and participant. Interviews took place once each participant had engaged in one-to-one sessions over a period of at least six months. The focus of the individual interview was to ask questions relating to the research objectives (listed in Section 2). Each interview was structured around the questions in Appendix B. These interviews were conducted by the psychologist in the role of 'researcher' (not the participant's treating psychologist) and lasted up to one hour. These interviews were digitally audio-recorded using a Samsung® digital voice recorder (DVR) and were later transcribed by the lead researcher.

The semi-structured interview questions (Appendix B) were informed by the literature on distress in palliative care (Mitchell et al., 2011; Chochinov and Breitbart, 2000), the application of mindfulness in clinical settings, including cancer (Piet et al., 2012; Baer, 2006) and the growing literature on symptom burden as a brief measure of quality of life (Morrison et al., 2017; Gapstur, 2007; Cleeland & Reyes-Gibby, 2002). The questions were largely targeted towards what is unexplored in the literature. For example, how do palliative care patients experience mindfulness and does mindfulness play a role in patient's self-management of distressing symptoms?

Three interviews took place in participants' homes, the fourth by appointment at one of the two hospice settings. Interviews varied in duration from 40 minutes to one hour depending on patient fatigue, concentration and completion of interview questions.

2.9 Data analysis

All of the data were transcribed and analysed using the methodology outlined in IPA (Smith et al., 2009). This is an active, iterative, and multi-phase process (Smith, 2004) that involves reading and coding participant transcripts to identify themes. This was done for each recorded interview. Data for each single case was analysed before moving to consider commonalities and differences across the entire sample.

2.9.1 Analytic strategy

The process of analysis began with detailed reading and re-reading of the transcribed manuscript. (A guideline of seven hours to every full recorded hour of interview is given by Smith et al., 2009; Pp.54). This facilitated immersion into the experiential world of the participant and was an opportunity to 'bracket' initial reactions arising from 'fore-structures' to its content (Smith et al., 2009; Pp.100). This phase was then followed by making initial exploratory notes and comments on the transcript. Observations on how a participant sees a particular issue, their use of language or anything of interest within the transcript was noted. As a guide, Smith et al. (2009) offer the categories of 'descriptive', 'linguistic' and 'conceptual' comments as a way of engaging with the transcribed material.

Once the initial exploratory noting was made, the next step was the generation of 'emergent themes' from the data-set. As Braun and Clarke (2013) have helpfully articulated, themes do not 'emerge' as a priori 'givens' within the data set. If this were the case, analysis by different researchers would lead to the same emergent themes. Rather, the analogy of the researcher as 'sculptor' engaged with the raw material of the data is a helpful one. This process included both the transcribed material and the 'new data' created by the researcher's engagement with the manuscript. The purpose was to encapsulate the 'psychological essence' of what was most salient from active engagement with a particular sequence of text. This is the 'hermeneutic circle' within IPA work – where the 'part' of one piece of text influences interpretation of the 'whole' and where the 'whole' influences interpretation of the 'part' (Smith et al., 2009; Pp.96).

The next phase of the analysis within single cases is to search for connections across themes. Again Smith et al. (2009) offered many possible ways to do this without being proscriptive. Developing 'super-ordinate' themes which involves grouping similar themes together either under a new name ('abstraction') or within an existing theme ('subsumption') are just two methods. These were most helpful in generating themes from the present study. Three additional methods of making connections across themes are 'numeration' (looking at the number of occurrences of a particular theme), 'function' (the specific function of the theme within the text, e.g., serving to position the participant as a 'victim' of a particular experience) and narrative 'contextualisation' (grouping themes in relation to the participant's overall narrative in relation to time). A visual representation (figure or table) of themes with representative examples from the transcribed material is the culmination of this phase of the analysis (this is presented in Table 3, below).

Throughout this phase of the analysis, capturing the researcher's own 'process' while attempting to collate identified themes is vitally important. This is an essential part of IPA and aids transparency as to the method. The final part of the analysis involved moving beyond single cases to consider the 'convergence' and 'divergence' of themes across the sample as a whole.

2.9.2 Assessing validity and quality

Unlike quantitative approaches, qualitative methods do not hold replicability as a guiding standard in assessing the quality and validity of research. This is largely due to the fact that both context (time and place) and the researcher's subjectivity intrinsically make the research findings unique (Braun & Clarke, 2013). This is where the philosophical starting positions and intentions behind a piece of research become important compass points. This is not to say that providing a clear and accurate account of the research process itself is not important. Indeed, the careful delineation of each step in the research process is essential if the conclusions are to be considered a valid understanding of the phenomenon in question. Yardley's (2000) four dimensions for assessing the quality of qualitative research, as well as Sandelowki's (2004) criterion of 'utility', will guide assessment as to the validity of this research (Braun & Clarke, 2013).

2.9.3 Methodological reflexivity

Ethical considerations were one of the most challenging aspects of this study, as the potential for 'dual role' conflicts with participants required careful consideration. Navigating the recruitment and consent of participants as well as the data collection process was also challenging. The fact that the target audience for this study were patients with extensive experience of mindfulness practice meant the sample of potential participants was small. This meant that the two psychologists working in the service occupied the roles of 'researcher' with participants not known to them. Furthermore, recruitment needed to take place in such a way as to allow participants choice and ongoing support regardless of their decision to participate.

Orne (1969) has outlined the importance of recognising ‘demand characteristics’ on research participants. These reflect ways in which the researcher may inadvertently influence participants through subtle cues such as the setting, explicit and implicit information about the goals of the research, as well as the person of the researcher her/himself. All of these factors may influence the quality of data obtained. Participants in turn may attempt to comply with what they imagine the researcher is hoping to find. Although this research was presented in an open, exploratory way, participants may well have modified their responses to ensure the data reflected positively on mindfulness.

Whereas demand characteristics reflect subtle pressures exerted by the researcher on participants, ‘experimenter bias effects’ reflect ways in which the researcher may engage in participant selection and data collection, analysis and presentation that results in a ‘Pygmalion effect’ or self-fulfilling prophecy (Rosenthal & Rubin, 1978). For example, the question of whether I could accept unremarkable findings occurred to me early in the recruitment phase. As a core therapeutic intervention offered to patients within the psychology service, my bias in seeing many potential areas of overlap between mindfulness and end-of-life could influence every aspect of this study. Indeed, the boundary between bias and interpretation was certainly to the fore during data analysis, which will be presented next.

3. Analysis

3.1 Overview

Table 3

Results table of superordinate and subordinate themes

Superordinate Themes	Subordinate Themes	Indicative Participant Quote
Developing new ways of relating to pain	Offers a sense of agency	"I can kind of say you know, 'I've pain there, that's fine. I've no pain there, that's fine." (John; 22)
	Alters medication use	"So I would actually say I would go without medication." (Tim; 44)
Regulating difficult thoughts and emotions	Calming effects of the practice	"…it's made me calm, it's made me calmer" (Tim; 132)
	Ripples and resonating effects	"[Medical Consultant] said, 'I've never had anyone breathing like you did!' [laughing] you know, and 'I'm going to tell my patients about this!' and I laughed." (Claire; 40)
A paradigm shift	A way of seeing	"Changing your perspective always changes what's going on." (Tim; 238)
	A way of being	"…definitely coincides with enjoying the present and if you don't know if you're going to be around in a year's time…em, that kind of helps I guess." (Conor; 76)
Cultivating and sustaining mindfulness	Power in simplicity	"How it would be presented would be vital. How people are introduced in very small ways for anxiety... I think that's very key." (Claire; 190)
	Making the practice one's own	"I kinda just went my own kinda path with it then really" (John; 86)
	Role of the teacher	"If you try to learn something from the internet and that, it can work but when you get to the little subtleties…you're gonna miss it." (Tim; 240)

Supervision during the analysis phase allowed me to see my implicit bias following the development of themes. Around this time, I also had a helpful conversation with a colleague familiar with IPA. He suggested this was what reflexivity in IPA was about. He succinctly said, “You need to interpret what you’ve been explaining.” Even though I believe I had interpreted the transcripts in developing the superordinate and subthemes, I had fallen into a trap of explaining the themes rather than offering a rationale for my interpretations of them. This meant the overall tone of the initial write-up was of attempting to convince the Reader of the merits of mindfulness. The obviousness of this was surprising, as I was aware of the potential of this happening from the outset. The fact that it seemed to happen regardless was quite shocking. This helped in returning to the analysis section with interpretation to the fore and the sceptic in mind. While I still caught myself being drawn into explanation, I was much more aware of it.

I believe this perspective, held more consciously, helped to off-set my implicit bias and led to a new depth of analysis. This resulted in further development of some of the themes. For example, the superordinate theme ‘A paradigm shift’ developed from ‘A changed perspective’. The subthemes also developed from ‘A different way of seeing/being’ to ‘A new way of seeing/being’ to finally, ‘A way of seeing/being’. These subtle shifts in language reflected my own subtle shifts in interpretation as I engaged with each interview transcript and then reflected on themes identified across the data set. The final themes (see Table 3, above) will be described next. Each superordinate theme along with its representative subthemes will be presented in turn. Indicative participant quotes reflect this second order interpretative analysis.

3.2 Superordinate theme 1: Developing new ways of relating to pain

All four participants spoke about their experience of mindfulness in relation to pain. This gave rise to the superordinate theme of ‘developing new ways of relating to pain’ and two subthemes – ‘offers a sense of agency’ and ‘alters medication use’. Prior to mindfulness training, participants (especially the two novice participants, John and Tim) reported that they found the experience of pain very difficult and struggled against it. Medication appeared to be the only way to manage it. This superordinate theme and subthemes seem to capture a different approach. Through a process of exploring the location and sensations of pain, often using the breath as a support, mindfulness seems to have offered another way of being in relationship to pain. This counterintuitive way of relating to pain also appears to have impacted medication use.

3.2.1 Subordinate theme 1.A.: Offers a sense of agency

The first sub-theme identified was that of developing a sense of agency in response to pain. This was characterised in different ways. For John, this seemed to be related to a sense of control:

“it allows me a bit of control in the sense that it allows my mind not to focus on it” (John; 58)

John appeared to be pointing to the mind’s role in pain perception in this quote. In particular, the mind’s tendency to focus on pain. Through mindfulness, it appeared that John had noticed the possibility of not getting so fixated on the pain. This freeing of attention seemed to offer a sense of control. The alternative for John was the experience:

“I’M IN PAIN” (John; 50)

The emphasis John placed on these words suggested he frequently felt distressed and completely dominated by the pain. In this sense it seems as if there may have been a reclaiming of John’s sense of self within the experience of pain, made possible by not being so overwhelmed by it.

Another aspect of ‘agency’ related to identifying regions of the body that were ‘pain-free’ at the very same time as pain was being experienced in other area(s) of the body. Both John and Conor spoke directly to this:

“I can kind of say you know, ‘I’ve pain there, that’s fine. I’ve no pain there, that’s fine.” (John; 40)

“I suffer a lot of headaches so you can…sort of, techniques to tease around the, you figure out, not, you’re not sore everywhere sort of thing…like that the pain is only in your head and only in certain parts of your head or whatever.” (Conor; 50)

Both quotes suggest an ability to relate more directly to the experience of pain. This seems to be somewhat courageous in the context of palliative care, where pain can take on extra significance due to the underlying diagnosis and prognosis. The capacity to simultaneously notice both the presence and absence of pain, as well as differentiate the boundaries of pain more clearly, seems to have added to John and Conor’s sense of agency. The willingness to engage with these unpleasant sensations mindfully also appeared to have led to experiencing pain with greater equanimity.

For Tim, mindfulness appeared to offer a way of interrupting unhelpful patterns of reacting:

“so I used to just blurt out things and that has stopped to a large degree. I’ve stopped and [breathes deeply] and then so I take, take charge of what is happening in terms of thoughts and the way things are happening.” (Tim; 24)

The degree to which mindfulness helped Tim to ‘take charge’ also speaks to this subtheme of greater agency. In this portion of the interview Tim gave a striking ‘live’ example of becoming less reactive through stopping and taking a mindful breath. The speed at which Tim responded to the initial set of interview questions, which seemed to be something that he generally used to do, as indicated by “just blurt out”, offered an insight into Tim’s cognitive processing before being able to do this. It seems that mindfulness may have played a role in slowing down his internal process to a more manageable level. This appeared to aid Tim in identifying the precise nature of his pain:

“to see if I’m…actually feeling what I’m feeling” (Tim; 36)

This seemed to offer a way to directly engage with the experience, perhaps overcoming a tendency toward experiential avoidance or reactive anxiety. The practice appeared to enable Tim to get a more accurate picture of things. It also appeared to inform what action (if any) he might need to take. For example, he later (Tim; 44) discussed his decision-making on whether to take medication or not in response to pain. For Tim, ‘where’ he located the breath was important:

“the breath is really important, where you place [attention on] the breath and for me that’s…in the middle of my being and so it grounds me.” (Tim; 8)

Here, Tim appeared to highlight the role the breath played in supporting him in the midst of pain. The physical location of the breath for Tim, in his solar plexus, may have had the effect of taking him out of his head/thinking and down into his body, which he experienced as more settling. This seemed to offer an alternative to an escalation of thoughts and feelings leading to rumination and/or avoidance which Tim alluded to above in “actually feeling what I’m feeling” in relation to pain. Although there was still a sense with Tim of his using the practice and the breath as a way of overcoming pain (Tim; 46), it is nonetheless significant that it seemed to offer him an alternative focus for his attention when pain arose.

Claire spoke about the breath as a way of being with severe pain:

“Well for that excruciating sharp pain, you know, I bring my awareness and I breathe” (Claire; 106)

Claire’s description of using the breath as a way of bringing awareness to pain suggests that even in relation to “excruciating sharp pain” she had some agency, there was something she could do. Claire also appeared to use mindfulness as a way of directing attention to the painful sensations themselves, with surprising insights:

“I actually bring my awareness to that sensation and it does move, you know, it does, it shifts” (Claire; 111)

Taken together, Claire suggested that by being aware of the pain and simultaneously being aware of breathing, led to a change in how the pain was experienced. Therefore, it seems as if it is not only that the focus of the mind shifts (to the breath and to physical sensations of pain), but so too does the physical experience of pain.

The descriptions above capture different ways participants used mindfulness in relation to pain. Mindfulness appears to change the perception of pain from something actively resisted or passively endured, to one in which they appeared to have a greater sense of agency and control. Interestingly, this led three participants to mention a perceived reduction in medication use when managing their pain, which will be presented next.

3.2.2 Subordinate theme 1.B.: Alters medication use

The second subtheme identified in ‘relating differently to pain’ was that of an alteration in medication use which was not specifically part of the semi-structured interview, but an interesting incidental finding.

For John, mindfulness appeared to lead to a reduction in the amount of additional medication required for pain.

“I think I’m certainly using less…‘break-through’ medication” (John; 154)

The ‘break-through’ medication referred to by John, refers to what he was taking in addition to regular pain medication. This is sometimes referred to as ‘PRN’ (‘pro re nata’) or ‘as needed’ pain relief. As noted earlier, John appeared to have developed the capacity to better identify the presence/absence of pain and this may explain part of his reduced need for medication. This may be similar to Conor, who also spoke about noticing ‘a definite change.’

“I did notice a definite, definite change but…wasn’t sure just how much of it was timing of the cycle of the symptoms” (Conor; 58)

Although Conor was sure he noticed a reduced need for pain medication that coincided with re-establishing a mindfulness practice, he was less certain about what gave rise to this. He suggested an alternative explanation that it was possibly due to the delayed effects of radiotherapy, which he knew from experience impacted “the cycle of the symptoms.” This uncertainty is a good reflection of just how multivariate and complex pain perception and pain management can be. However, it appears that Conor believed mindfulness may have played some role. It is interesting to speculate what the cause or mechanism of action of this may have been, such as his greater ability to clearly identify the boundaries of pain (see 3.1.1).

For Tim, the effects of mindfulness meant there were times when he did not need to take additional pain relief:

“So I would actually say I would go without medication.” (Tim; 44)

Tim’s experience of sometimes not requiring medication is very significant. Given his ability to engage more directly with pain and his debilitating “power-outs” (see 3.1.1), this is likely the result of feeling generally more in control. The consequences for Tim and Conor in reducing the amount of medication they were taking seemed to have been significant, as it meant they were less likely to experience the iatrogenic effects of the pain medication, which they each stated required further pharmacological intervention.

Tim also described a pattern of mindfulness-informed medication use.

“I would have to come back out and say, ‘Right, I’m done’ and then, so the mindfulness would be set aside, and I would just go on normally with everything, going with the medication.” (Tim; 45)

Although Tim seemed to see this as a ‘failure’ of his ability to use mindfulness to ‘overcome’ the pain, it was rather an example of his ability to respond skilfully by deciding to take medication when required. Tim’s apparent sense of failure will be explored further in the next chapter (see 4.2.2).

3.3 Superordinate theme 2: Regulating difficult thoughts and emotions

All participants spoke about mindfulness in relation to difficult thoughts and emotions. Whether in relation to thoughts of disease progression or managing the frustration associated with immobility or side-effects of medication, mindfulness appeared to offer a way of meeting difficult experiences.

3.3.1 Subordinate theme 2.A.: Calming effects of the practice

Three participants specifically mentioned the ‘calming’ effects of mindfulness practice. This seemed to change their relationship to themselves and consequently, to the world.

“It’s not that you’re cutting the outside world…out, it’s that you’re calming your inner world…down” (John; 122)

“you see things more…you’re calmer” (Conor; 14)

The quote from John, above, seemed to point to a capacity to self-monitor and self-regulate difficult emotions. John was careful to point out this was not through withdrawing from or negating the external world but rather by engaging with his interior experience. This may be because precious attentional resources were directed inwards, where they are likely to have maximum benefit. Conor’s statement alluded to mindfulness allowing him to ‘see more’. The prospect of attaining a more complete picture of things through a greater experience of calm, as Conor attests, will be unpacked further in the Discussion (see 4.3.1.).

The impact of bringing mindful awareness to the frustration associated with medication side effects was mentioned by Tim:

“it’s made me calm, it’s made me calmer” (Tim; 132)

The effect of this for Tim appeared to be in relation to interrupting thought-affect cycles that could compound and make his experience of challenging symptoms even more difficult. In this example Tim was able to use the breath and engage in self-questioning to help slow his internal process. As observed above (see 3.2.1), Tim noticed a tendency towards anxious reactivity when experiencing unpleasant sensations and his use of these two strategies appeared to help focus his attention in the present moment.

Two participants also spoke about the effects of mindfulness specifically in relation to thinking. For example, Tim stated,

“It takes me out of thinking solidly always about cancer” (Tim; 30).

Mindfulness seemed to offer Tim an alternative to unhelpful rumination. Perhaps the “solidly always” refers to the kind of fixed perceptions that can end up trapping us in unhelpful thinking (Williams et al., 2015). This shift in thinking may also reflect Williams' (2008) distinction between 'being' and 'driven-doing' modes of mind. Rumination appears to be based on a hostile relationship with the present moment and the way things are. Rumination idealises a goal as preferable to the current state of things (e.g. being cancer-free) but gets stuck in the 'gap' between the idealised state and the current state, further compounding the difficulty (Segal et al., 2013). Claire spoke about using the breath to interrupt negative thoughts in relation to disease progression:

"…believing that cancer had spread to my brain…And I took my deep breaths and [said to myself] 'Well, we don't know yet'" (Claire; 135).

Claire gives an example here of just how powerful thoughts can be. Her ability to recognise thoughts as thoughts and direct her attention instead to her breathing, seems to have allowed her to see that "thoughts are not facts" (Segal et al., 2013, p.314). This appears to have allowed her to substitute a more realistic thought, "we don't know yet", which was also more accurate. As a neutral focus of attention, the breath seemed to offer Claire a place of stability amid distressing rumination about disease progression. A more neutral focus on the breath, seems to have allowed her to achieve a more balanced perspective.

3.3.2 Subordinate theme 2.B.: Ripples and resonating effects

Given palliative care's aim to address the impact of life-threatening illness on family members and close relationships, this subtheme reflects how mindfulness can affect others. At least three participants spoke about the relational impact and ripple effects of mindfulness.

Tim spoke about having learned to mindfully respond to sudden episodes of complete energy loss, which he called 'power-outs' and the effect this had on his immediate family:

"…this changes the response of everyone around me." (Tim; 88)

This was said with a sense of surprise and insight, suggesting Tim was acknowledging for the first time, the wider impact of meeting these kinds of situations more mindfully. He went on to emphasise this further by saying,

"…so you think of *my* mindfulness but actually it's, it's boiled over into other people…" (Tim; 89)

which seemed to be an acknowledgment of the wider repercussions on others. Implicit in this seems to be a sense of responsibility Tim had for how his illness impacted on others and that there were aspects of this he could manage more effectively. Tim's more mindful approach (accepting and 'going with' the experience and waiting for his energy to return) to these episodes of ‘power-outs’ appeared to directly impact the behaviour of his wife and daughter. For example, it allowed them to recognise without fear or distress that when Tim was experiencing a ‘power-out’ he simply chose to lie on the floor with a towel and blanket while he waited it out.

“[Tim] has a ‘power-out’ again…. What do you need? Anything?”

Therefore Tim’s ‘power-outs’ appeared to have become normalised as part of everyday experience within the family and were able to be communicated without high levels of distress.

In the context of previously high expressed emotion around these kinds of episodes, this observation appeared to be particularly important for Tim.

For Conor, the interpersonal effects of mindfulness were mentioned when asked about any other areas of his life where the practice may have made a difference. This was most recognisable for Conor in terms of noticing the effects of speech:

“Definitely would catch yourself getting cross or snappy.” (Conor, 19/11)

“…if you said something you shouldn’t say, you’d notice quicker.” (Conor; 143)

Mindfulness appeared to offer Conor a kind of internal witness or monitor that was more interpersonally sensitive. This greater awareness of how his words impacted others appears to have been beneficial, perhaps by allowing him to acknowledge the effects of what was said and respond more skilfully.

The impact of Claire’s mindfulness on medical staff arose following her ability to remain mindful during an unpleasant angiogram procedure. Her Medical Consultant seemed particularly impressed:

“[Medical Consultant] said, ‘I’ve never had anyone breathing like you did!’ [laughing] you know, and ‘I’m going to tell my patients about this!’ and I laughed.” (Claire; 40)

This quote reflects how Claire’s mindfulness seemed to both surprise and impress her doctor. The ripple effect of Claire’s practice on both her immediate exchange with her doctor, as well as potentially on her doctor’s future interactions with other patients, offers a practical example of how mindfulness may be useful both instrumentally and inter-personally. Claire’s joy in recalling the experience was also apparent in her retelling of this exchange, as it offered an opportunity for greater connection. It also seemed to have inspired her medical consultant to become a mindfulness advocate. This is significant as Claire appears to be offering something back to the medical system here, simply through her ability to remain mindful.

The examples above from Conor, Tim and Claire highlight how mindfulness can have ripple effects on the quality of personal relationships and will be explored further in the next chapter.

3.4 Superordinate theme 3: A paradigm shift

The extent to which mindfulness seemed to play a role in changing experience through a changed perspective is one that was shared in different ways by all participants. This appears to be a process where the initial experience is changed through an act of perception (i.e. becoming mindful). This change in perspective appeared to take two general forms – a way of seeing and a way of being. Both are likely highly inter-related processes. The effects of this appear to change how the initial experience is subsequently experienced. This process seems to have been especially noticeable in relation to unwelcome or unpleasant experiences. Although this superordinate theme relates to enhanced emotion regulation, it appears more closely linked to perception and to what has been termed a "paradigm shift" in medicine (Kabat-Zinn, 2013, p.371).

3.4.1 Subordinate theme 3.A.: A way of seeing

Participants consistently reported that the way in which they viewed things, through the intentional application of mindfulness, changed their perspective which in turn seemed to change the experience. For example, John spoke about a shift in perspective in relation to his immobility and inability to leave his bedroom, due to illness:

Interviewer: "And then when you come back out then, you're still in the same room, but what's different?"

John: "What's changed is me." (John; 132)

This statement captures something of a paradigm shift, where John's willingness to practice mindfulness in the context of being frustrated and bed-bound, led to experiencing it differently. As nothing in the (external) situation had changed other than John "calming my inner world…down" (John; 121) through mindfulness, his internal experience appears to have been very different. Indeed, there is an extent to which John was no longer the same person, "What's changed is me." This changed self no longer seems to be as impacted by the situation as before. It is as if the part of John that was experiencing this situation as severely challenging has gone into abeyance, through mindfulness. Akin to the pain experience, it is almost as if the reactive part of John has been assuaged, allowing him to be less identified with the limits of the situation.

Similarly, Tim spoke about the impact of a changed perspective in relation to pain:

"…it changes your perspective on what's happening at the time...I'm not reacting in the same way." (Tim; 196)

In this quote Tim shares that practicing mindfulness can lead to a different view of things. Interestingly, this seems to have acted as a kind of habit breaker. The practice appears to have led to both perceptual and behavioural change. In these ways it could be seen as leading to a different way of seeing and acting. Given this quote came in the context of Tim speaking about pain, it appears that mindfulness allowed new ways of viewing and reacting to pain to become possible. In fact, this possibility, of mindfulness leading to a change in perspective, appeared central to Tim when asked why he would recommend mindfulness to other patients receiving palliative care:

"Changing your perspective always changes what's going on." (Tim; 238)

In this quote Tim offers a reminder of how powerful a change in perspective can be. This may take on even more significance in advanced illness, where a person's view of what is happening can remain relatively independent of physical limitations and consequently have a major impact on quality of life.

The fact that experience itself seemed to change the perspective of two participants who were initially sceptical of mindfulness, highlighted another interesting aspect of this theme. For example, Conor stated,

"…the fact that you just had to do, not believe it but just do what it said to do and it worked…you could see that it [was] working after a few weeks like, was…fascinating, I thought" (Conor; 10).

Similarly, John spoke of how his perception of mindfulness changed with experience:

"…because I'd have been probably one of the 'nay-sayers' with regard to whether I would have thought it would be useful to me or not" (John; 2).

From these quotes it appears that both Conor and John came to see mindfulness in a new light following their experience of practicing it. Neither scepticism nor belief appeared to have been barriers to practice. Rather what seems implicit is that both shared a certain openness towards engaging in the practice, resulting in a changed perspective.

Perhaps most pertinent in the context of palliative care, it seems as though developing mindfulness may also impact one's perspective on death. Both Claire and Conor spoke about mindfulness in relation to themes around end-of-life.

“It’s something about a natural progression to my death and mindfulness has somehow taken the fear out of it.” (Claire; 169)

Claire appears to suggest a link between mindfulness and how it can diminish fear of dying. It appears that the role of mindfulness in addressing the fear associated with dying, allowed Claire to see death as a natural part of life. This also accords well with MBCT (Segal et al., 2013), as when fear is present, this may limit one’s ability to see things clearly.

Conor recommended mindfulness in the context of palliative care by quoting the writer/poet/mystic, William Blake, who advocated a very different way of seeing:

“I have a favourite quote. (Pause) Think it’s William Blake. (Pause) Em, I think it’s very good for people with, em, well, don’t know how long they have. But eh, ‘To see the world in a grain of sand, And heaven in a wildflower, Hold infinity in the palm of your hand, And eternity in an hour.’” (Conor; 159)

“…well to me it means like ‘eternity in an hour’, you know?” (Conor; 161).

It appears that Conor has found a way to take up Blake’s invitation to experience ‘eternity in an hour’ through the practice of mindfulness. These lines seem to offer Conor a perspective that allows him to live with the uncertainty surrounding prognosis in a way that transcends the ordinary, everyday view of things to one that is deeply meaningful.

In the context of palliative and end-of-life care, this takes on special significance and was the basis on which Conor advocated mindfulness for others in palliative care:

“…just try it, try it for a week or two.” (Conor, 157)

3.4.2 Subordinate theme 3.B.: A way of being

Noticing the effects of bringing kindly attention to the present moment was another common subtheme, particularly in relation to difficulty. Claire spoke about this in a practical sense in relation to medical procedures, as well as the uncertainty of her disease status:

“Anytime I go for a CT scan, I don’t mind. Some people get claustrophobic. I just close my eyes and I just meditate.” (Claire; 9/22)

CT scans offered Claire an opportunity to practice mindfulness. This seems like a courageous and creative response to what can often be a highly stressful experience. The fact that Claire chose to direct her attention in this way, rather than get pulled into the kind of thought-affect spirals that could lead someone to feel claustrophobic, seemed to offer her another way of being. Claire captured more precisely how the practice supports her in the following quote:

“I would usually be more conscious about coming into the moment and breathing and being present” (Claire; 10/14)

It appears that the practice supported Claire in potentially challenging circumstances such as awaiting a CT scan by offering her an alternative to rumination and worry. As Claire suggests, this is something she must consciously decide, otherwise it is likely attention will be drawn into the past or the future. The breath is also mentioned as a useful ally in the work of being present, as it is intimately connected to the present moment. This seems to have offered Claire a way of being that was a creative response to the situation she was in, as well as allowing her to exert her own agency in an otherwise anxiety-inducing situation.

Tim also spoke to this way of being in relation to managing pain. By using a series of questions to help anchor his awareness in the present moment, Tim was able to acknowledge what was really happening and what action, if any, he needed to take.

“I would stop to think, ‘Where am I? What am I doing? Where am I placed? Right...What am I feeling?’ And then I would start saying, ‘Right, I’m feeling pain. Where am I feeling pain?’ So, I go through the whole mindfulness set to think, ‘What is going on?’ And then it gets to a place where…the pain. Sometimes the pain is not bad, and I would actually go without medication…” (Tim, 44)

Although this quote is rather heavily thought-based (perhaps indicating a tendency towards rumination), Tim’s ability to engage in a question-and-answer dialogue with his direct experience appears to have allowed him to identify the nature of that experience more clearly. It seems this allowed Tim to experience the reality of pain rather than getting lost in thought-affect spirals about/around the pain. The fact that this sometimes led to a realisation that medication was not required, suggests that this ability to stay present to the reality of things, allowed new insights to emerge and consequently led to new choices in behaviour. So not only does this appear to have allowed Tim a new way of being in relation to pain but also a way of being in relation to himself, that allowed him to see and respond to experience more accurately.

The ability to inhabit the present moment in the context of living with the uncertainty of a life-threatening illness was specifically mentioned by Conor:

“definitely coincides with enjoying the present and if you don’t know if you’re going to be around in a year’s time…em, that kind of helps I guess.” (Conor; 13/9)

Conor appears to suggest that mindfulness is associated with developing an appreciation for the present moment, as something to be savoured in itself and most especially in the context of end-of-life. This way of being, of deliberately focusing attention in the ‘here and now’ regardless of time remaining, seems to have offered Conor a way of making the most of life. This appears to have supported Conor’s wellbeing while living with the stress associated with the uncertainty of prognosis.

3.5 Superordinate theme 4: Cultivating and sustaining mindfulness

The final superordinate theme reflects participants’ experience of cultivating and sustaining mindfulness. Cultivation in this context refers to the process of learning mindfulness and the conditions that have proven helpful for learning. Sustaining mindfulness refers to those aspects of the practice that participants have found important in continuing to support and develop their practice over time. The subthemes below reflect both aspects.

3.5.1 Subordinate theme 4.A.: Power in simplicity

The first subtheme identified was that where learning mindfulness is concerned, there is power in simplicity. For example, based on his experience, John had a clear sense of what practices were helpful for him:

“…they’re very simple and they’re very basic and I just kinda stuck with those.” (John; 6/29)

John’s experience of keeping things simple appears to have been sufficient for him. He appears to imply that while he was aware of more complex or advanced practices, he has not needed them. Given the plethora of mindfulness resources and technological platforms available, it appears that simplicity works. In a similar vein, Tim spoke about the amount of time needed to start benefitting from mindfulness when learning it:

“No, it doesn’t take time…It actually is really quick.” (Tim; 27/9)

It appears that mindfulness may be adopted quickly by some patients receiving palliative care. Usually, mindfulness training programmes are taught in 2-3-hour blocks, once a week for eight weeks. Given the uncertainties around health status, symptom burden and time, it is helpful to know that an extended period of mindfulness training is not always necessary in a palliative care context.

The importance of how mindfulness is initially presented to patients was another aspect of the power in simplicity:

“How it would be presented would be vital. How people are introduced in very small ways for anxiety... I think that’s very key.” (Claire; 37/2)

Claire stresses the importance of how the practice is presented to those experiencing anxiety. As the presence of anxiety is likely to make the learning of new skills more difficult, Claire's quote is particularly insightful. Indeed, this may also be part of its appeal to John, as mentioned above. This points to the importance of making the practice accessible in ways that are likely to be of immediate benefit and avoiding complexity which could escalate anxiety. The role of the teacher also seems to be implicated here, some aspects of which will be presented in 3.5.3, below.

3.5.2 Subordinate theme 4.B.: Making the practice one's own

Each participant spoke about making the practice their own. This appears to be an especially important aspect of keeping the practice alive, accessible and personally relevant. For example, John spoke about two practices that he made his own:

"I kinda just went my own kinda path with it then really, em. Two things are, the kinda exercises that I kinda use is focusing on where I am physically, like where I'm touching the bed or my weight on the bed. And I'd do the same as you, feel my heels on the bed and work my way up the body. And the other one I'd use then would be [the] breath." (John, 86)

John mentions two mindfulness practices that have a clear focus or 'object' of attention as well as a strong attentional training component to them. It is perhaps no surprise that one of the main outcomes John reported was that of 'calmness'. This type of focused attention (FA) training is considered one of the main types of mindfulness practices and is often emphasised when first learning mindfulness formally.

Tim pointed to how internalising the practice over time allowed it to be available to him during a 'pain spike':

"So, I'm actually doing the talk [self-guiding a mindfulness practice]. I'm doing the talk as well to see if I'm if I'm actually feeling what I'm feeling." (Tim, 36)

This quote from Tim seems to indicate an internalising of the mindfulness practice guidance, 'the talk.' This allowed the guidance to be available to him in the critical moment, such as in response to pain. Perhaps similar to effective psychotherapy (when the client successfully internalises the attitudes and empathy embodied by the therapist), it is interesting to speculate whether a similar process of internalisation begins to happen in mindfulness training.

The ebb and flow of sustaining a mindfulness practice over time was articulated by Conor.

“it’s hard to keep it up so the refresher courses, like I’d stop for a while and then try to keep it up, or see an app’ and sign up for that, or do a refresher course and that gets me going again” (Conor; 1/11).

It seems that Conor acknowledges just how difficult it can be to sustain a mindfulness practice over time. He mentions several different, creative ways that have helped him to re-engage with it. This has allowed Conor to sustain a practice over 6-7 years. Another important aspect of sustaining a practice for Conor was that of having a group to practice with:

“even a group of people doing it, I don’t know why it seems to make it easier” (Conor; 6/2).

Given Conor’s extensive experience of mindfulness, this aspect of group or community is worth exploring further in the discussion. This may take on additional significance in the context of palliative care.

3.5.3 Role of the teacher

The role of the teacher in both cultivating and sustaining mindfulness was another aspect of this superordinate theme shared by participants. For example, John emphasised the role of the teacher in verbally guiding mindfulness practices:

“But I think for people who are practicing it, it would be important for them to have someone to orate the session.” (John, 254)

Although John had developed considerable experience in practicing mindfulness, he valued the role of the teacher in offering verbal guidance. As John mentioned this in the context of feeling a lack of confidence in guiding himself (contra to Tim’s experience of “doing the talk” mentioned above), this points to the importance of ongoing, regular support for a certain cohort of patients.

Conor also explicitly spoke about the role of the teacher in guiding mindfulness practices:

“it’s much easier, doing it with a person leading you than an app’ leading you” (Conor; 5/31)

As mindfulness ‘apps’ offer audio recordings of often very experienced mindfulness teachers, Conor appears to suggest there is an added benefit of the teacher being present to guide the practice ‘live’. Given the emphasis placed upon ‘embodiment’ and responsiveness to the present moment in training mindfulness teachers (Crane et al., 2013), it is perhaps not surprising to see this subtheme identified in the data. Tim appeared to develop this subtheme further when he spoke about the importance of the teacher in communicating the subtleties of mindfulness, over and above a reliance on technology:

“If you try to learn something from the internet and that, it can work but when you get to the little subtleties…you’re gonna miss it.” (Tim; 26/19)

Furthermore, Tim appeared to suggest that teacher training and experience was important and ultimately an aid to learning mindfulness:

“It’s quick to learn if someone teaching it is good.” (Tim; 27/10).

Tim’s quotes suggest that when it comes to learning the intricacies of mindfulness, the role of the teacher and their training matters. There may also be a deeper interpretation to be made in relation to embodiment. In essence, the teacher is modelling a way of being with a difficult experience or suffering that reflects certain attitudinal foundations of mindfulness (Kabat-Zinn, 2013), e.g. curiosity, patience, openness, nonjudgment, trust. In much the same way as the client may internalise the person of the therapist in effective therapy (Duncan et al., 2010), how the teacher responds to difficulties that arise with someone learning mindfulness may become a model for how the individual relates to difficulty in their own life.

Finally, although Claire did not specifically mention the role of the teacher, she stressed that how mindfulness is offered in the context of illness was key:

“So I think people who are ill…how it’s presented to them [is] really, really important” (Claire; 37/9).

Taken together the quotes above suggest that although there may be a role for technology, the teacher’s role in embodying, guiding and communicating the nuance of mindfulness practice is important. This aspect of embodying the practice and its significance in teaching will be developed further in the discussion.

4. Discussion

4.1 Introduction

In this section, themes identified from the analysis will be discussed with reference to relevant literature from areas such as cognitive psychology and Buddhist literature. This section is also written with leading qualitative researchers' recommendation to make explicit the utility of qualitative research findings (Braun & Clarke, 2013; Sandelowski, 2004; Yardley, 2000). Many of the subthemes correlate with proposed mechanisms of mindfulness that help to explain its effects. These models are frequently underpinned by research from neuroscience. Findings from the analysis will be clarified and the clinical and practical implications discussed. Learning from and limitations of this study will then be presented and recommendations for future research outlined. As reflexivity is integral to IPA research, the chapter concludes with a final reflective summary on the overall experience of conducting this research.

4.2 Superordinate theme 1: Developing new ways of relating to pain

Given that healthcare-oriented mindfulness first developed for people with chronic health conditions including chronic pain (Williams & Kabat-Zinn, 2013), it is perhaps no surprise that developing new ways of relating to pain was the first superordinate theme identified in the data. As management of pain is a key component of palliative care, participants' comments on this theme are particularly pertinent. The International Association for the Study of Pain (2020; para.3) defines pain as: "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage."

This definition includes an understanding that pain is what a person says it is. The presence of physical pain was shared by all participants. This also represented the greatest source of physical symptom burden. In fact, most participants did not mention significant difficulty in relation to any other physical symptoms e.g. fatigue, nausea, anorexia, breathlessness. This does not account however for the psychological, social or spiritual burden of disease, which can often compound the experience of pain (Zeidan & Vago, 2016; Kabat-Zinn, 2013; Cassell, 2013; Kearney, 1999).

The subthemes offer a unique insight into how participants' relationship to pain changed. This is conceived within MBSR/MBCT as revealing the nature of suffering (Teasdale & Chaskalson, 2011a), particularly that of 'primary' and 'secondary' suffering (Burch & Penman, 2013). Sometimes this is spoken about as the difference between pain and suffering, where the experience of pain becomes compounded, leading to secondary suffering. Physical pain is an excellent example of this, as outlined in the original Buddhist teaching (the Sallatha Sutta; Saṃyutta Nikāya 36:6) and described in section 1.1.2.

The decision to consciously bring attention to physical sensations of pain seems inherently counterintuitive. However, in counteracting habitual patterns of denial and avoidance (that can often compound the experience of pain), it accords well with mindfulness-based cognitive therapy (Segal et al., 2013). Mindfulness involves a willingness to recognise habitual/automatic reactions and instead explore pain as multidimensional, comprised of physical sensations (e.g. burning, stabbing, pulling/dragging, pins and needles etc.), feelings about the pain (e.g. anger, frustration, guilt, depression, anxiety), thoughts about the pain (e.g. "I cannot cope with this much longer"; "How long will I have to put up with this?"), as well as impulses to act in different ways (e.g. to withdraw, stop socialising, seek further medical treatment).

This kind of open, curious approach to what is essentially unwanted or difficult, is often referred to in MBPs as 'turning towards difficulty' (Bartley, 2012; Williams & Penman, 2011) and often represents a pivotal stage in these programmes. In developing the capacity to engage with pain in this way, it appears from the testimony of participants in this study as well as evidence from neuroscience (Zeidan & Vago, 2016), that it is possible to uncouple the experience of pain 'unpleasantness' (thoughts and feelings about the pain) from pain 'intensity' (subjective ratings of pain severity). Interestingly, mindfulness of the body (physical sensations) is also the first of the four foundations of mindfulness as outlined in the Buddhist teaching on mindfulness. As such, it can act as a reliable foundation from which to develop mindfulness of other aspects of experience, such as feelings and thoughts.

To whatever extent it may be possible to cultivate a different relationship to pain, in a palliative care context this is likely to take on extra significance. The present study appears to be the first of its kind to provide examples of such a possibility within the context of palliative care.

4.2.1 Subordinate theme 1.A.: Offers a sense of agency

The reality of being diagnosed with a life-limiting illness often means that a person has spent considerable time in the health system. The changes brought about by diagnosis and prognosis are often profound and can pervade every aspect of a person's life. The sense of agency captured by this subtheme could be understood as participants' reclaiming responsibility, including a more literal sense of ‘response-ability’ in relation to pain. This fits with the principals of integrative medicine (Bell et al., 2002), where the patient retains as much responsibility for their healing as is often expected from the medical system. Healing, in the sense in which it is meant here, is that of “coming to terms with things as they are” (Kabat-Zinn, 2013, Pp.409). This is not a passive position but reflects a conscious choice and capacity. It also includes an enhanced ability to respond and take action if required.

For John, Tim and Conor, the ability to investigate the boundaries of pain appeared to lead to a changed relationship to it. This is likely a result of enhanced interoception (Craig, 2002), the ability to identify internal bodily states, specifically physical sensations. Interoception in turn is an aspect of ‘body awareness’, one of a set of proposed key mechanisms of mindfulness (Hölzel et al., 2011). For example, John offered a glimpse into how his relationship to pain shifted from one in which he would state, “I’m in pain” to one in which “I can kind of say you know, ‘I’ve pain there, that’s fine. I’ve no pain there, that’s fine.” The psychological journey between these two statements is subtle and yet potentially profound. The second statement arguably reflects a more sophisticated internal position in relation to pain. The possibility of holding these two conditions in awareness with equanimity, appears to be something that can be learned and trained. It has also been proposed as a key outcome of mindfulness training (Desbordes et al., 2014). This may represent what Suzuki (1949, Pp.88) described as, “the unfolding of a world hitherto unperceived in our dualistic minds” i.e. the co-existence of both pain and no pain, simultaneously. The alternative is likely to remain stuck in a cycle of reactivity and aversion (Segal et al., 2013; Goldstein, 2013) likely borne of heightened threat appraisal (Lazarus & Folkman, 1984; Kabat-Zinn, 2013) where the pain narrative continues to dominate.

What can compound the experience of pain for many is the narrative that gets built up around the experience. Mindfulness appears to help with interrupting this narrative (Farb et al., 2011; Teasdale and Chaskalson, 2013b; Segal et al., 2013; Allen et al., 2009). Burch (2008) has outlined two common patterns of reacting to chronic pain, which can lead to habitual tendencies of feeling and acting. These patterns, comprised of thoughts, feelings and behaviours associated generally with the extremes of ‘denial’ or ‘overwhelm’, were exemplified by John and Tim when reacting to pain before learning mindfulness. Through mindful engagement with pain, which was calming for John and through a series of questions which helped to clarify the experience for Tim, both seemed to regain a sense of agency and self in relation to painful sensations. Although Tim used the phrase “…to see if I’m feeling what I’m feeling” it is evident that he is speaking here about ‘sensing’. This is mindfulness of the body *in vivo*. This process of reducing suffering has already been proposed from a Buddhist-informed, cognitive psychology perspective (Teasdale & Chaskalson, 2011b).

Claire's experience of directing awareness to the breath and to the physical sensations of pain, seemed to allow her to recognise that pain is not a fixed entity. This experiential learning that pain morphs and changes over time appeared to give Claire some confidence in relation to using mindfulness with pain. From an experiential learning perspective, mindfulness could be seen as a means of allowing recognition of certain truths about the nature of reality – such as that of impermanence (Goldstein, 2013). Within the experience of pain, mindfulness seems to allow the person to engage directly with what is happening (if they choose to do so) rather than disengage or deny or attempt to block out the experience, which can end up compounding it. Mindfulness is fundamentally about choosing how to be in relationship with whatever we are facing (Kabat-Zinn, 2013). For Claire, the changing nature of experience, especially in relation to severe pain, seemed important. The availability of the breath as a place to focus attention when experiencing pain, inevitably means that not all of one's attentional resources are taken up by the experience of pain. The breath as a potentially more neutral focus of attention appears to offer an alternative to the experience of even very severe pain (Zeidan & Vago, 2016).

This sense of agency and ability to better identify physical sensations is likely the result of body scanning and developing a greater sense of connection to the body. Indeed, the standard 8-week MBSR programme is designed with deepening one's connection to the body in mind. The neuroscience of mindfulness has reflected this in studies that have sought to combine fMRI studies with cognitive models in attempting to map explanatory mechanisms of mindfulness. For example, two prominent models (Vago & Silbersweig, 2012; Hölzel et al., 2011) have identified the role of enhanced body awareness as central to mindfulness. This is particularly pertinent in the context of pain where the ability to uncouple thoughts and feelings from physical sensations appears to be associated with a reduction in pain sensitivity (Zeidan & Vago, 2016; Burch and Penman, 2015; see also Norman Farb's (2007) work on two distinct neural modes of self-reference).

4.2.2 Subordinate theme 1.B: Alters medication use

Although mindfulness gained momentum in western healthcare as a programme for people with chronic health and pain conditions through MBSR, it was not conceived as an alternative to the medical model or pharmaceutical therapies. Rather, its intention was always to work in tandem with whatever best medical treatment is available, as an adjunctive treatment approach (Kabat-Zinn, 2011).

Tracking drug use is one obvious objective measure to gauge the effectiveness of non-pharmacological interventions for pain. However, the fact that pain is complex, frequently multidimensional and of different aetiologies should caution against making any simplistic claims about an intervention's effectiveness. Although three participants noticed significant alterations in medication use, two were explicitly cautious about attributing a causal relationship to mindfulness. Nonetheless, this does suggest that mindfulness may well have a role to play in some aspects of pain. Indeed, this may be an overall effect – the whole (or combination of all subthemes) being greater than the sum of its parts when it comes to pain management. Given the greater levels of equanimity reported by participants in relation to noticing a range of physical sensations, this reflects that perhaps the first foundation of mindfulness (of the body) was established.

Regardless of what aspect(s) of mindfulness were responsible for participants' reduced medication use, this appeared to be the result of something they were able to do for themselves, i.e. change how they were relating to the pain. The incidental finding that this may lead to a reduced need for additional pain control is not without precedent (Garland et al., 2020, for a recent review). Although reductions in drug use were purely anecdotal and a result of multiple complex factors, this may yet be the first time this finding has been recorded in a palliative care sample.

By way of reflecting some of this complexity, I wanted to return to a subtle aspect of using mindfulness in relation to severe pain. After initially describing his 'success' with using mindfulness as a way to reduce or prevent the need for medication, Tim also described (Tim; 44) becoming frustrated that he could not use his mind (mindfulness) to always 'overcome' pain. He went on to describe how he would then, at a certain point 'give up' and choose to take his prescribed PRN pain medication. Tim's description shows how what was wise "discernment" (Goldstein, 2013), i.e. choosing medication as opposed to continuing to experience pain, was interpreted by Tim as failing to use mindfulness to 'overcome' pain. This is an important conceptual understanding those teaching mindfulness should seek to clarify. The aim is the cultivation of mindful awareness of experience and how this can ultimately inform the choices one makes – not defeating or overcoming difficulty but choosing how to be in wise relationship to it.

4.3 Superordinate theme 2: Regulating difficult thoughts and emotions

The ability to regulate one's internal world, specifically in relation to difficult thoughts and emotions has been proposed as a mechanism of mindfulness from both a cognitive (Segal et al., 2013; Teasdale & Chaskalson, 2011a), and neuroscientific perspective (Lutz et al., 2007; Hölzel et al., 2011; Vago & Silbersweig, 2012; Davidson, 2003; Farb, 2007). For example, Hölzel et al. (2011) proposed enhanced emotion regulation as the third component in their four-factor model. This was conceived as comprised of positive reappraisal and nonreactivity. Vago and Silbersweig (2012) developed this in their self-awareness, self-regulation, self-transcendence model (S-ART), with emotion regulation a key factor in the self-regulation component.

Mindfulness of feelings (vedanā in Pali) is considered one of the four foundations of mindfulness in the Buddhist canon, the Satipaṭṭhāna Sutta (Anàlayo, 2003) in which experience is characterised as having an independent associated feeling of either 'pleasant' or 'unpleasant' or 'neither pleasant nor unpleasant'. How one reacts to the associated 'feeling-tone' or vedanā in the moment is seen as crucial in determining the extent to which we may unwittingly compound our suffering or distress (Goldstein, 2013; Segal et al., 2013; Kabat-Zinn, 2013). Once an experience is judged as 'unpleasant' for example, this sets up a cascade of aversive reactions, comprised of negative thoughts, feelings, physical sensations and behaviours. Even though there may be little that can be done about the experience itself, it may be possible to remain mindful of one's reactions.

Although not a literal translation of thoughts, mindfulness of mind (the third foundation of mindfulness) includes thoughts as one aspect of mind to which we can attend. Interestingly the Buddhist tradition sees mind as a sixth sense, along with the other five senses of taste, touch, sight, sound and smell. Therefore, the mind (and thoughts) can be attended to just as any of the other sensory objects or 'doors' into the present moment (Kabat-Zinn, 2013). The identification of thoughts and feelings is central to MBCT teaching. Distinctive exercises focusing on these aspects of experience, which are so relevant to depressive relapse, form the basis of its departure from MBSR.

In the present study, each participant offered real-world examples of bringing mindfulness to highly charged emotional situations. These included physical pain, hospital scans, medical procedures, as well as thoughts of disease progression. The subthemes capture some of the effects of being mindful in such situations, particularly in relation to working with difficult thoughts and feelings.

A subtle but conceptually important aspect of mindfulness emerged in Claire's interview. As this was not a shared theme among participants generally, it does not form part of this superordinate theme. However, Claire expressed her disappointment and frustration that her mindfulness practice had not been able to help her through a significant depressive episode. (This was similar to Tim's frustration that mindfulness could not always guarantee less reliance on pain medication, see 4.2.2 above.) This reveals an important assumption about how mindfulness is sometimes understood. From a mindfulness perspective, given that it is synonymous with 'kindly awareness' of *whatever* is being experienced, it is perhaps most helpfully conceived of as "a way of being" (Kabat-Zinn, 2013, p.413). Where frustration or disappointment may arise is when we fall into the trap of assuming a causal relationship between the practice and things changing for the better. Bringing a curious, gentle, kindly awareness to whatever we are experiencing may change the experience, and/or it may simply allow sufficient time to pass to for us to experience change as the inherent nature of reality.

4.3.1 Subordinate theme 2.A.: Calming effects of the practice

The 'calming' effects of mindfulness practice represented by this subtheme is highly consistent with clinical, neuroscience and contemporary Buddhist literature. For example, the entire Buddhist teaching on mindfulness has been summarised by Anàlayo (2014) as "keep calmly knowing change" (Pp.87). The 'calmly' aspect is seen as representing the effects of a stable attention, undistracted by desire or aversion.

In the neuroscientific literature, the calming effects of mindfulness are most often associated with focused attention (FA) practices where attention is directed towards a single focus or object of attention. The effects of this training have been studied closely (Lippelt et al., 2014; Tang et al., 2015, for review) and involves regions of the anterior cingulate cortex in alerting, orienting and sustaining attention.

The physiological effects of calming or FA practices is most likely the result of parasympathetic activation and down-regulation of the stress response, specifically patterns of activation of the HPA (hypothalamic-pituitary-adrenal) axis that prime the body for fight, flight or freeze (Vago & Silbersweig, 2012; Hölzel et al., 2011; Siegel, 2007; Davidson et al., 2003). Although this outcome was explicitly referred to by three participants, it is understood as an indirect effect of the practice as 'trying to relax' is more likely to create tension than lead to a reliable experience of relaxation. It is for this reason that mindfulness is sometimes referred to as a paradoxical approach (Shapiro et al., 2018) – it appears to lead to change through not directly pursuing change.

Conor’s ability to ‘see things more’ was a good example of his perceptual capacities remaining open and aware. This may be as a result of greater emotion regulation where one’s attention is not becoming stuck or limited to a portion of the perceptual field. The consequences of this kind of view in the context of palliative care is that it offers the potential to remain open to more aspects of experience and not to be limited by illness or an illness narrative. Indeed, this is precisely what Bates (2016) found in a similar study.

The ability to identify very threatening thoughts of disease progression and to intervene in ways which may de-escalate one’s internal response are practical examples of the potential for mindfulness in palliative care. Key to MBCT effectiveness is making what is implicit in CBT explicit, seeing “thoughts as thoughts” (Segal et al., 2013; Pp. 302). Claire’s example of using the breath as a way to acknowledge reality in the moment seemed to interrupt ruminating on disease progression. This is a good example of metacognitive awareness or awareness of thinking. The ability to ‘see’ thoughts as thoughts and choose to take attention to the breath and engage in more supportive self-talk. These examples point to ways in which mindfulness practice may be able to aid calm and interrupt unhelpful rumination.

4.3.2 Subordinate theme 2.B.: Ripples and resonating effects

How we are has the potential to affect the people we meet. In the context of serious illness and potentially charged interactions with medical staff and family members, the ability to assume responsibility for how one responds to others is a good example of what Kabat-Zinn (2013) calls ‘People Stress’. Review studies, including within palliative care, with both informal caregivers (Li et al., 2016; Jaffray et al., 2016) as well as healthcare professionals (Burton et al., 2017; Irving et al., 2009), have consistently reported beneficial effects of mindfulness on mental health, caregiver burden and quality of life, especially when this includes a focus on self-compassion (Raab, 2014).

Claire and Tim’s examples of practicing mindfulness and then seeing its ripple effects on their close personal relationships are powerful examples of how interconnected we all are. The implications of these kinds of interactions in the context of illness, as we saw with Claire and Tim, is likely to be highly significant.

Although there may be many aspects of illness that are not within a person’s control, these examples offer glimpses of how palliative care patients can exert control over interactions with other people, which can potentially be a major source of stress. This has the potential to not only mitigate the effects of stress on the people we meet but to also add to a sense of our own wellbeing. Tim’s example of using mindfulness to manage potential ‘distress contagion’ was also observed by Dekeyser et al. (2008).

Conor’s ability to better ‘read’ the emotional landscape in his interactions with others is another aspect of interpersonal mindfulness. Research, particularly from psychotherapy, supports Conor’s view that mindfulness enhances empathy (Germer et al., 2013; Davis & Hayes, 2011; Block-Lerner et al., 2007). The neuroscience of ‘mirror neurons’ mean that terms such as ‘empathic resonance’ now have a compelling (albeit not certain) neurological basis (Bruce et al., 2010; Siegel, 2009).

The direct and indirect effects of mindfulness on healthcare professionals, as reported by Claire, exemplify ways in which mindfulness can have ripple effects on others. Not only was Claire able to regulate her own body and emotions with obvious personal benefit but this was noticed by the physician carrying out the angiogram, presumably lowering his own stress levels. The fact that he was further inspired to share this with Claire and intended to encourage other patients to do likewise, is likely to have added to Claire’s wellbeing at the time and again on recounting it. We now know from the neurobiology of mindfulness that this is likely to have direct beneficial effects on Claire’s physiology and mental state.

4.4 Superordinate theme 3: A paradigm shift

Just as one cannot ‘un-see’ something once it has been ‘seen’, this superordinate theme attempts to capture a radical perceptual shift, usually through the perceiver being changed – not the external situation. Although challenging to articulate, this superordinate theme perhaps best signifies the kind of internal relational shift towards experience that is possible through mindfulness. As it represents an internal process which is experienced, any attempt to articulate it will at best be an approximation and at worst miss the point completely. Perhaps an analogy might help to clarify what is meant by this.

Imagine, for example, one is waiting patiently in a queue. Then, someone appears to ignore the queue and heads straight to the front of the line. One might justifiably feel angered by this. Until that is, one sees that the person has a walking cane and is in fact visually impaired. Suddenly one’s feelings about the situation may completely change. Rather than feeling angry, perhaps one now feels calm, curious and empathic. Nothing has really changed except how one is viewing the situation, which alters it completely. Although not exactly analogous, the ability to be mindful offers the potential to come into a different kind of relationship with whatever may be happening in the moment. This kind of internal shift requires a ‘rotation in consciousness’ and has been referred to as a “paradigm shift” (Kabat-Zinn, 2013, p. 371); nothing (external) has changed but everything (internally) has changed.

This physical-mathematic reference to a new paradigm or “orthogonal rotation” in consciousness (Kabat-Zinn, 2013, p. 793) helps to describe the new landscape in which someone now finds themselves. This appears to be more than ‘decentring’ or meta-cognitive awareness (Segal et al., 2013) and has been captured by models on mechanisms of mindfulness by terms such as ‘self-transcendence’ (Vago & Silbersweig, 2012), as well as ‘change in self-perspective’ (Hölzel et al., 2011). There is a degree to which the calming, stabilising effects of attention and emotion regulation enable this shift in perspective to take place.

All four participants spoke about instances in which they experienced a change in perspective as a result of mindfulness practice. For John, this was both in relation to pain, as well as the frustration associated with being immobile. Similarly, Tim recommended mindfulness based on its ability to break patterns of reactivity in relation to pain and other symptoms. Both Conor and Claire spoke about a changed perspective in relation to living with an awareness of dying. Significantly, Tan et al. (2017, pp.339) hypothesised just such a possibility:

“In addressing suffering at the end of life, we have been “looking outside” for solutions most of the time, without realising that “looking inside” may unveil better solutions and thus create a paradigm shift that can potentially change the landscape of psychosocial care completely.”

This study lends support to Tan et al.’s (2017) hypothesis. The subthemes below appear to give voice to just this kind of internal shift.

4.4.1 Subordinate theme 3.A.: A way of seeing

Segal et al. (2013) have outlined our capacity for ‘metacognition’ as a key mechanism of MBCT for depression. This ability to see ‘thoughts as thoughts’ and not as facts, appears to play a pivotal role in making what is implicit in CBT, explicit in MBCT. It could be argued however that MBCT goes further, encouraging the person to also bring awareness to how they are relating to different aspects of experience – thoughts, feelings, body sensations and impulses. As mentioned, this can make all the difference with regard to secondary suffering.

It is interesting to speculate what participants' experience may have been without mindfulness. For example, John's description of being stuck in the same room "24/7" revealed a change in self perspective that seemed to paradoxically offer him a way out. This appears to have been possible through first consciously recognising his frustration. It seems the practice offered John an alternative to thoughts and feelings of frustration and loss. This is a good example of Hölzel et al.'s (2011) model of the mechanisms of mindfulness – greater body awareness, enhanced attention regulation and emotion regulation, leading to a change in self-perspective, "What's changed is me." (John; 9/22). Indeed, the neuroscience and cognitive science of mindfulness is pointing towards a change in mode of mind and experiencing that supports a change in self perspective (Farb et al., 2007; Williams, 2008) that is arguably akin to John's statement. The reactive part of John has gone 'offline' to be replaced, at least temporarily, by a calmer more accepting aspect of self.

The kind of radical perspective articulated by Conor through invoking the words of William Blake, arguably transcends the psychological to a more wholistic or spiritual view. The extent to which Conor can access or intuit what Blake meant in his famous 'Auguries of Innocence' poem (c.1803) suggests that mindfulness may offer a doorway into a connection with nature and ultimately to experience "eternity in an hour." This appears to be the territory of self-transcendence articulated by Vago and Silbersweig (2012) in their S-ART model. Conor appeared to be able to draw inspiration and solace from Blake's words, linking them to what mindfulness meant to him personally. Poetry and other art forms can do this like nothing else. This is an example of the kind of 'implicational meaning' that cannot be reduced to the sum of its individual parts and which has been proposed as key to the transformation of suffering (Teasdale & Chaskalson, 2011b).

Perhaps there was some resonance in this for Claire too in what she struggled to articulate around the effects of mindfulness and fear of dying. It may have been the case that the practice freed her from a narrative around dying. As soon as one adopts a more mindful or decentred approach to experience, there is the possibility of bringing kindly awareness to suffering and to experience less suffering as a result. In recognising the difficulty in articulating experiences such as Claire grappled with, perhaps it is enough to acknowledge a possible relationship between mindfulness and a reduced fear of dying. The Buddhist doctrine of "anatta" or 'no fixed self' (Thanissaro, 2011) is instructive here. The ability to adopt a decentred (Segal et al., 2013; Teasdale & Chaskalson, 2011b) relationship to thoughts, feelings and other contents of consciousness appears to offer the potential for freedom from suffering.

4.4.2 Subordinate theme 3.B.: A way of being

Staying present seemed to offer an alternative to uncertainty in the context of palliative care. The ability to bring attention back to the present moment was considered a defining feature of ‘homo sapiens’ by the father of western psychology, William James:

“The faculty of voluntarily bringing back a wandering attention, over and over again, is the very root of judgment, character, and will... An education which should improve this faculty would be the education par excellence.” (James, 1890, p. 463)

The extent to which this allowed participants experience a new way of being in relation to the uncertainty of medical procedures, fear and prognosis (Claire), prognosis and time (Conor) or physical symptoms (John and Tim) reflects a more conscious relationship to experience. This has been conceptualised as gently ‘turning towards’ difficulty (Bartley, 2012; Segal et al., 2013) and is the opposite of experiential avoidance. Although this shares some features of exposure to unwanted experience (Treanor, 2011), the intention informing this attentional and attitudinal stance is not one of attempting to overcome or ‘fix’ the problem. Rather, this reveals a kind of portal or entrance into the paradox at the heart of mindfulness for health conditions – that cultivating the capacity to allow experience to be as it is, without fixing, changes it (Shapiro et al., 2018). More accurately perhaps, it is the willingness to allow things to be as they are, that allows one to experience change. The fact that this is an orientation to experience that participants can bring to it themselves, makes this both portable and reliable in any situation.

Claire’s quote on this subtheme was almost identical to the operational definition of mindfulness quoted in the Introduction (1.1.1) in the example she gave of bringing mindfulness to a highly stressful situation. The “more conscious” reflected the ‘on purpose’ part of the definition. Her “coming into the moment and breathing” reflected the ‘present moment’ part and “being present” captures a way of being with ‘things as they are’.

Mindfulness also offered a new way of being in relationship to pain that acknowledged there was more to experience than just the pain. This appeared to offer Tim and John a way of retaining a sense of self in relation to pain. The extent to which our sense of self may collapse around the experience of pain appears to be universal. Indeed, this is central to understanding the ‘Second Noble Truth’ in Buddhism. We will likely suffer to the degree to which we avoid experiences we do not want, or ‘cling’ to experiences we do want (Teasdale & Chaskalson, 2011a).

4.5 Superordinate theme 4: Cultivating and sustaining mindfulness

Given the centrality of mindfulness as a practice, over and above being a concept or set of ideas, these themes reflect participants' learning and development of mindfulness over time. Agricultural metaphors and use of the verb 'bhavana' from the Indian Sanskrit language meaning 'to cultivate', are deliberately used within Buddhist literature to reflect this kind of inner work. There is a sense in which over time, mindfulness acts as a kind of inner preparation and tilling of the soil of the mind/heart. As mentioned in the Introduction, mindfulness could equally be translated as 'heartfulness' and without this understanding, is incomplete (Feldman & Kuyken, 2019; Kabat-Zinn, 2011; Santorelli, 1999).

Although not consistent across all participants, some themes such as initial scepticism, trust in one's inner experience, and the role of technology in supporting mindfulness practice are helpful additional themes for clinicians to consider. Claire was very clear in her recommendation that mindfulness be offered in ways that are immediately accessible and useful to patients.

4.5.1 Subordinate theme 4.A.: Power in simplicity

The information provided by John, Tim and Claire in this subtheme is especially revealing in the context of a specialist medical population, where there may be a lot of complexity. In essence, their experience that simple practices are sufficient (John); that mindfulness is quick to learn (Tim); and that it should be introduced in ways that avoids complexity (Claire) offers clinicians helpful guidance when offering mindfulness in palliative care.

Given the explosion of interest in mindfulness in many aspects of healthcare, society, and popular culture (The Mindfulness Initiative, 2020), there are now a vast array of potential mindfulness practice programmes and resources available in many different formats. Although aware of some of these, John chose to 'keep it simple' in terms of his own practice. This seemed to be sufficient for John and offered him what he needed. Both Tim and Conor used the support of a guided audio practice from a recommended and well-recognised source (Williams & Penman, 2011). Although Claire had the longest established practice (over twenty years), she continued to practice with audio guidance for the body scan practice.

The usual expectations of reward gained for effort made when it comes to learning a new skill becomes somewhat more nuanced in relation to mindfulness practice. This is because the intention is always "to be here, now" (Killingsworth & Gilbert, 2010, p.932). Although experience 'counts' in terms of being more fully present, more often, the allusiveness of the present moment makes it a constant practice – some would say a “relentless” practice (Kabat-Zinn, 2013, p.822).

Although the ‘gold standard’ programmes of MBSR and MBCT have the biggest evidence base, only two of the four participants in this study learned mindfulness in this format. The fact that both John and Tim had individually ‘tailored’ one-to-one mindfulness sessions over a period of at least six months, appeared to offer a useful alternative. Although this is somewhat resource intensive, the results point towards the potential for counselling psychologists and other members of the healthcare team to offer mindfulness in this way. For example, there is the potential for physiotherapy sessions to be delivered mindfully, either as part of a ‘mindful movement’ practice and/or as part of the clinician’s own self-care. As Claire alluded to, when offered to patients experiencing (mild-moderate) anxiety or fear, simple ways in which to stabilise and ‘ground’ attention in the present moment can be very supportive.

4.5.2 Subordinate theme 4.B.: Making the practice one’s own

The challenge of sustaining a mindfulness practice over time is shared by even enthusiastic advocates of mindfulness. Although there is a small but significant positive relationship between ‘home practice’ and outcome measures in those attending the standard eight-week programmes of either MBSR or MBCT, the relationship appears more complex than simply logging hours of formal practice (Parsons et al., 2017). For example, the quality of attention rather than simply ‘time spent’ practicing may be an important variable.

Interestingly in this study, it was the two participants with the longest established practice of mindfulness – Conor (6-7 years) and Claire (20-plus years) – who explicitly mentioned their struggle. Claire struggled with her practice for a very specific reason – a deep depression borne of grief. As discussed above, Claire was somewhat embarrassed by this, believing that mindfulness should have protected her from becoming depressed. However, even during depression, Claire was able to sustain a connection to some aspects of her practice on a regular basis.

Conor’s experience was one of finding creative ways to re-establish a regular practice once he became aware that he needed to reconnect with it again. Indeed, this was the basis of his referral to the palliative care psychology service. He recognised his increased anxiety around an upcoming set of brain scans and requested support around this.

Although John and Tim did not explicitly discuss their struggle with maintaining a practice, neither appeared to have established a regular practice. Rather, their impulse to engage in mindfulness practice appeared to be prompted by negative or unpleasant experiences, such as pain, low mood or frustration. These motivations to re-engage in mindfulness practice offer further support for the potential utility of mindfulness in palliative care. Regardless of motivation, the fact that participants were drawn back to the practice as a way to support themselves, appears to indicate its importance to them.

4.5.3 Subordinate theme 4.C.: Role of the teacher

Given the growing interest in mindfulness-based approaches (Creswell et al., 2019) and the need for high quality research (Rosenkranz et al., 2019), there has been significant progress in recent years in articulating the core competencies of mindfulness-based teaching (Crane et al., 2013). The Bangor-Exeter-Oxford 'Mindfulness-Based Interventions Teaching Assessment Criteria' (MBI:TAC; Crane et al., 2017) was the result of a collaboration between three of the main university-based mindfulness teaching programmes and has been widely praised and adopted by training organisations worldwide. The MBI:TAC outlines six domains of competency, each with a subset of 'key features' indicative of the domain in question. One of the domains, 'Embodiment', includes the key features of 'present moment focus', present moment responsiveness', 'steadiness and vitality', 'allowing' and the 'natural presence of the teacher'.

Many of the 'key features' listed above are likely to have resonated with participants in the present study at some level, especially with John, Tim and Conor who appeared to prize the role of the teacher over and above audio recordings. Indeed, even Claire's emphasis on how mindfulness is introduced in small ways for those who are fearful, implied a sensitive matching and tailoring of the guidance to the patient by a skilled teacher. Embodiment was also a key theme discovered by Van Aalderen et al. (2014) in their qualitative study of the role of the teacher in MBIs. Both teachers in this study received extensive training to teach mindfulness and had been offering mindfulness to patients in palliative care for many years. They are therefore likely to have scored in at least the 'competent' range or above on the MBI:TAC.

As mentioned in the analysis (see 3.5.3), the significance of being accompanied (Crane et al., 2015) by the mindfulness teacher into an exploration of unpleasant physical sensations such as pain, or unsettling feelings such as anxiety, or thoughts of the future may yet prove to be a key mechanism of mindfulness. This counterintuitive 'turning towards' unwanted experience (Segal et al., 2013; Bartley, 2012; Williams & Penman, 2011) is already recognised as part of the paradox of mindfulness (Shapiro et al., 2018). Much as in psychotherapy, perhaps internalising the attitudinal foundations (Kabat-Zinn, 2013) of mindfulness as embodied and implicitly communicated by the mindfulness teacher, offers another way of being in relation to difficulty. This process may be somewhat analogous to cultivating a secure base (via the breath and physical sensations) in attachment theory (Bowlby, 2005) and psychotherapy (Kahn, 1997). Over time, through the internalising of the stabilising presence of the parent or therapist or mindfulness teacher in this case, we may learn that it may be possible to do this for ourselves.

4.6 Strengths and Limitations

The fact that participants had extensive experience of practicing mindfulness prior to recruitment was a strength of this study. Where participants were new to mindfulness, regular individualised sessions over a minimum time period of six months ensured they received extensive mindfulness training. This decision was informed by previous studies in palliative care where practice experience was often limited to just a few minutes. Adhering to six months as a minimum basis for inclusion meant that participants were not novices. However, what was a strength in terms of inclusion, limited the number of participants eligible for recruitment.

An additional strength of this study was the fact that both mindfulness teachers had extensive experience (over 20 years combined) of teaching mindfulness both in individual and group settings in palliative care. This allowed them to tailor their teaching to the particular participants' needs in this study. However, researchers who conducted the participant interviews were the same psychologists working within the palliative care service. This meant acting as researcher to participants not known to them. This is an unfortunate limitation and would ideally be avoided in future studies, as participants were aware of a professional connection between researcher and clinician/mindfulness teacher.

The programme form of mindfulness offered to participants was mainly based on the MBCT-derived, *"Mindfulness: Finding Peace in a Frantic World"* (Williams & Penman, 2011) programme. The physical demands of a full MBSR or MBCT programme would have been neither possible nor appropriate for this cohort. Rather, for three of the four participants, these were essentially bespoke, one-to-one mindfulness trainings. This rests upon in-depth knowledge of the main 8-week evidence-based programmes of MBSR and MBCT, as well as extensive experience and implicit embodied understanding of offering these in modified form in palliative care. There are both strengths and weaknesses associated with this. The strength of such an approach is that it can be tailored to the individual, including clarifying conceptual issues around practice that may arise within or between sessions. The weakness is that it is difficult to manualise and therefore replicate faithfully.

Although IPA (Smith et al., 2009) is inherently context-dependent and can be carried out on a single case-study basis, the fact that it was possible to recruit just four participants, limits the confidence with which these findings can be generalised. However, the quality of data gathered offered insights into the potential for mindfulness in palliative care. For example, evidence was found for the paradox of mindfulness in palliative care, as proposed by Beng et al. (2017). Furthermore, two practices not usually part of these programmes appeared to be particularly helpful to participants in this setting. These were: i). Explicit moment-to-moment verbal labelling of experience as ‘pleasant’, ‘unpleasant’ or ‘neither pleasant nor unpleasant’; and ii). The deliberate noticing and switching of attention between areas of pain and non-pain in the body.

A further limitation of this study was the absence of participant reported ‘adverse events’ in relation to practicing mindfulness. Future studies of mindfulness in palliative care should include a thorough series of questions investigating the presence/absence of adverse events. Such possibilities were highlighted by the work of Britton (2019) and Dobkin (2017), especially in relation to meditation practice within religious/spiritual practice communities. Although the semi-structured interview was generally value ‘neutral’, participant reports may well have been subject to ‘demand characteristics’ (Rosnow, 2002) and experimenter bias. Subtle influences such as Interviewer vocal tone or inflection at certain parts within the interview may have reflected experimenter implicit value judgements and conveyed interest in more ‘positive’ representations of mindfulness. This could be addressed in future studies by asking participants directly about adverse events or experiences. The extent to which participants may have wanted to portray mindfulness in a positive light, given they were still receiving a service from the palliative care team, is an important factor to consider when assessing validity. A clearer separation of roles of researcher/clinician may also have helped in this regard.

Braun and Clarke (2013) have summarised some of the key quality criteria when assessing qualitative studies. Helpfully, Sandelowski (2004) frames the assessment of qualitative research in terms of its practical utility and has encouraged researchers to make this explicit. Yardley (2000) offered four criteria to assess qualitative research. These are: i. Sensitivity to context; ii. Commitment and rigour; iii. Transparency and coherence; and iv. Impact and importance. The reflexive, context-dependent nature of IPA lends itself well to fulfilling the first three of these criteria. However, criticism may be levied on the basis of ‘commitment and rigour’ due to the small number of participants recruited and therefore lack of data saturation. Reflective of Sandelowski’s (2004) utility criterion, although its impact and importance are both local and individual, in sharing their experiences participants have contributed to understanding the role and potential of mindfulness in palliative care.

4.7 Recommendations for future research

Although many avenues for future research exist, comments here will be limited to the learning and findings from this study. As this research has reported on the possibility of cultivating a different relationship to pain within palliative care, this outcome deserves further study. For example, this study provided evidence of a mindfully informed medication use. At times mindfulness acted as an alternative to medication and at other times informed the timeliness and need for medication. Future research could help to further unpack the relationships between mindfulness practice (using a practice diary), regular symptom assessment (e.g. ESAS scale/ PCOC score) and medication-use.

The effectiveness of mindfulness with different pain types (e.g. muscular, neurological, bone), as well as delineating the cognitive-affective components of different stages (early, middle or end-stage) of disease are other possible research streams. An enhanced ability to discern and articulate thoughts, feelings and body sensations means that mindfulness training itself may offer a means to get more ‘experience-close’. Continuing to use IPA as a framework to understand such experience may help to inform medication and care-giving practices within palliative care.

Participant and patient voices are powerful data in mindfulness research. Given the intrusiveness of fMRI and EEG studies, continued efforts to translate and progress mixed methods and qualitative approaches with objective data such as medication use, as well as third party observations could serve to further explain the mechanisms and potential of mindfulness in palliative care. For example, Elliot’s HSCED research design (2002) employs a Helpful Aspects of Therapy form which could be modified to track meaningful moments from individual mindfulness sessions.

Findings from this study are limited by sample size. A longer recruitment phase of at least one year would allow for a larger sample size and ultimately greater saturation of themes. This would also allow patients new to mindfulness to continue to build their experience and understanding of the practice, while more experienced participants are being recruited.

However, it is important to acknowledge the challenges to recruitment inherent in this context where uncertainty exists around time, disease progression and prognosis.

Instances where participants unconsciously defaulted into the same patterns of judgment of mindfulness, that initially compounded their distress are worthy of future study. For example, Tim's sense of inadequacy to use mindfulness to relieve pain and Claire's in relation to preventing an episode of clinical depression, point to the importance of being alert to patterns of mind that maintain distress, now with regard to mindfulness (Teasdale & Chaskalson, 2011b; Williams & Penman, 2011). Reporting instances such as these in the clinical and pedagogical literature around mindfulness reinforces the limitations of conceptual modes of mind in the domain of suffering.

This study provides preliminary evidence that a suite of short practices embedded in a mindfulness programme specifically tailored to palliative care patients can be beneficial. Future studies could also investigate its utility especially targeting the final weeks and days of life. Clinical and anecdotal experience would suggest it may be especially useful at this time. Although this was not identified due to the relative disease stability of participants in this study, it is likely to prove a rich and powerful area of future research.

4.8 Reflexive statement

As I reflect on the study as a whole, I am especially grateful to Claire, John, Tim and Conor, who generously offered insights into the role mindfulness played in their lives. Although there are obvious shortcomings and limitations in this study (see section 4.7), this should not diminish the potential of these findings to inform the emerging field of palliative psychology. Two practices appear to have been particularly helpful – the ability to acknowledge the precise location or absence of pain in the body as well as the ability to identify experience as pleasant/unpleasant/neutral.

Mindfulness appeared to offer a tangible alternative to participants in certain situations such as experiencing pain, awaiting scans and undergoing unpleasant medical procedures, as well as living with the uncertainty of disease progression. This research has answered some initial questions and raised many more. For example, do individualised mindfulness sessions offer an advantage over group-based formats when communicating the subtleties of mindfulness as applied to serious illness? Does the extent to which a person has internalised the practice make it more available in challenging situations?

Precisely as a response to what can often seem like a need to offer more with less time, this is one area that would do well to withstand the demands and pressures of the healthcare system. Managers and fellow staff members open to mindfulness can be helpful allies in this. Those members of the MDT interested in providing mindfulness to patients will need to prioritise and protect the time needed to offer mindfulness training to patients in a way that can be usefully internalised and made available. Although this would ideally happen long before the person requires palliative care, the likelihood is that this will require time and commitment on both sides. This means beginning with the healthcare professional her/himself.

Despite the fact that most were initially sceptical, participants in this study recommended mindfulness for others receiving palliative care with the proviso that it is not presented in an over-complicated or burdensome manner. Rather, participants suggested skilful ways in which to offer mindfulness in this context, e.g. live guidance; short, simple, accessible practices. If it becomes a part of a patient’s repertoire of self-care or self-regulation, it may be especially useful when challenged by circumstances or symptoms. It also appears to offer a means of stepping out of narrative mode of mind to direct experiencing. Participants also made a case for the importance of the training of those offering mindfulness. A regular personal practice, excellent knowledge of the pedagogy of mindfulness and extensive teaching and training experience are essential elements. This may allow mindfulness-based palliative care to become more widely available.

Historically, mindfulness has positioned itself as adjunct to mainstream healthcare rather than as an alternative to it. While there appears to be strong support for it from participants in this study the challenge will be to communicate the value of this approach to healthcare providers and patients themselves, ideally long before they require palliative care. Mindfulness will remain a key therapeutic stance in my own work. To the extent to which it points to dimensions of experiencing and knowing that are beyond the conceptual mind, more in the direction of Blake's 'eternity in an hour', mindfulness seems to offer a means of connection between patients and healthcare professionals. This may enable both to live fully and with appreciative awareness for each other on the threshold between life and death.

4.9 Conclusion

This has been a learning journey in relation to IPA (Smith et al., 2009) and has led to a deepening appreciation of it as a method for revealing participants’ perspectives, as well as my own. There was much richness in the interviews, and I hope the interpretation offered here does them justice. The role of reflexivity in acknowledging personal bias and enabling the analysis to go deeper is highly congruent with Counselling Psychology's humanistic basis and prizing of the phenomenology of lived experience.

On the basis of themes arising from the analysis, mindfulness appears to have a role to play in whole person palliative care. This was exemplified in relation to emotion regulation, perceptual change, as well as a mindfully informed medication use. Many factors appear to influence the extent to which patients use mindfulness in palliative care, not least the presence of physical pain and anxiety. Mindfulness is fundamentally relational. An important message from this research is how we approach experience matters. When approached with mindfulness, even the most challenging aspects of human experience appear to be workable.

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Appendix A: Participant mindfulness training following referral (to Psychology)

Number, duration and content of mindfulness training sessions

Participant	Number of sessions	Duration of sessions (mins)	Content of sessions	Materials
John	26	30	Body Scan	MFPIAFW*
			Breath and Body	MFPIAFW*
			Vedanā practice+	'Live' guidance
			Naming practice++	'Live' guidance
Tim	22	30	Body Scan	MFPIAFW*
			Breath and Body	MFPIAFW*
			Vedanā practice+	'Live' guidance
			Naming practice++	'Live' guidance
Conor	9	30	Body Scan	MFPIAFW*
			Breath and Body	MFPIAFW*
			Vedanā practice+	'Live' guidance
			Naming practice++	'Live' guidance
Claire	6	30	Body Scan	'Live' guidance
			Breath and Body	'Live' guidance

*MFPIAFW is 'Mindfulness: a practical guide to finding peace in a frantic world' (web-based app' and audio recordings; Williams & Penman, 2011). The practices outlined in this 8-week programme acted as a framework for learning mindfulness, particularly for the two participants new to mindfulness, John and Tim. The two practices emphasised most were the Body Scan and Breath and Body. (Due to physical disability, John was unable to engage in the mindful movement practice associated with Week 3.)

'Live' guidance refers to in-session guidance offered by the psychologist in the role of 'clinician'.

+Following a brief (5-10 mins) period of focused attention, 'Vedanā practice' involved opening awareness to *labelling any single salient aspect of present-moment experience* (thoughts, feelings, body sensations, sounds) as ‘pleasant’, ‘unpleasant’ or ‘neither pleasant nor unpleasant’. The practice involved alternate ‘turn-taking’ with the mindfulness teacher, during a 10-minute practice period. This practice aids the ability to identify present moment experience and its associated ‘feeling tone’.

[++] Following a brief (5-10 mins) period of focused attention, ‘Naming practice’ involved *naming and locating* the presence of ‘pleasant’, ‘unpleasant’ or ‘neither pleasant nor unpleasant’ *sensation in the body*. The practice involved alternate ‘turn-taking’ with the mindfulness teacher, during a 10-minute practice period. This practice emphasises the ability to identify the existence and changing nature of different types of physical sensation, along with their associated ‘feeling tone’.

As both the ‘Vedanā’ and ‘Naming’ practices require some familiarity with orienting, sustaining and switching attention on particular aspects of present moment experience, these may be considered somewhat advanced practices. As such, they were introduced following the standard 8-week framework of MFPIAFW with John and Tim as a way to deepen their practice. As Conor had a pre-existing mindfulness practice prior to engaging in the ‘top-up’ programme of MFPIAFW, Conor was introduced to these practices at an early stage. Claire (who had the longest established mindfulness practice) was not introduced to these practices.

Appendix B: Interview Schedule

The purpose of this interview is to hear about your experience of using mindfulness in the context of receiving palliative care. The following questions are offered as prompts to get a deeper understanding of how you have been using the practice and your thoughts and feelings about it. As far as possible, this interview is also an opportunity to engage in a mindful dialogue together, informed by the same qualities of mindfulness we have been cultivating within the practice over the past number of weeks. As such, either one of us might choose to pause the conversation at certain points, particularly if it seems we have wandered away from the question at hand and bring attention back to the present moment e.g., to the breath. So, to begin, how would it be to take a brief pause together? (Pause). Thank you.

1) Firstly, can you say how it has been to practice mindfulness over the past number of months?

a. Did you have a pre-existing practice, or did you come to it through palliative care?

b. How has it been to develop your mindfulness practice alongside what has been going on for you medically?

c. Does anything stand out for you?

2) Has practicing mindfulness made any difference to how you manage your illness?

a. In what way(s)?

b. Can you give an example of when you last used the practice to support yourself in your illness?

c. Are there particular times when you are more likely to practice mindfulness?

d. Has it made a difference to how you think about illness?

3). Of the following list of symptoms, please indicate which have been most problematic for you over the past month: pain, tiredness, shortness of breath, loss of appetite, sleep difficulties, emotional problems, other ___________. [Participant may choose several] Does mindfulness make any difference to how you experience and manage these symptoms? [Ask about using mindfulness in relation to each symptom nominated]

4) Has practicing mindfulness made any difference to how you view yourself/ your sense of self? Your illness?

5) Would you recommend mindfulness to others receiving palliative care? Why/Why not?

6) Is there anything else you would like to add?

Appendix C: Academic Ethics Approval

Mon 11/03/2019 11:44
Approved Ethics

Dear David,

Your ethics application form has been approved by the Psychology research ethics panel and by the Chair of the Research Ethics Committee from the School of Social Sciences. You can proceed with your research recruitment process.

--
Kind Regards,

Angela

Dr Angela Ioanna Loulopoulou, PhD; AFBPsS; FHEA

Principal Lecturer in Counselling Psychology
Programme Director of the Professional Doctorate in Counselling Psychology
School of Social Sciences
Chair of Subject Standards Board for PG Psychology
Chair of Ethics Review Committee for PG Psychology

Appendix D: Clinical Research Ethics Approval

St. Vincent's University Hospital
ST. VINCENT'S Elm Park, Dublin 4, www-stvincents.ie+353 1 221 4000 UNIVERSITY HOSPITAL D04 T6F4t Ireland

{tm Park

[redacted]

27th March 2019

Ref. No.: RS19-011
Experience of mindfulness in palliative care — an interpretative phenomenological study
Cover letter 06.03.2019. Application Form v2 05.03.2019. Patient Information Leaflet &
Consent

Dear [redacted]

I refer to your correspondence dated 6th March 2019, in response to ours of 26th February 2019. Following review of your responses and clarifications, this study has been granted full ethics approval.

Please note, it is the responsibility of the Principal Investigator to retain complete file of submission and approval documentation.

Yours sincerely,

Dr Rachel Crowley
Chairperson
Ethics & Medical Research Committee

cc. Mr David Shannon, Senior Psychologist, [redacted].

Appendix E: Patient Information Leaflet

STUDY TITLE: Experience of mindfulness in palliative care.

NAME OF PRINCIPAL INVESTIGATOR: David Shannon

You are being invited to participate in a research study. Thank you for taking time to read this.

WHAT IS THE PURPOSE OF THIS STUDY?

Little is known about the experiences of palliative care patients who have developed a mindfulness practice. The purpose of this study is to interview up to 6 patients with at least 6 months experience of mindfulness to understand the role of mindfulness in the context of receiving palliative care.

WHY HAVE I BEEN CHOSEN?

You have been asked to participate because you are receiving palliative care from [redacted] and have been practicing mindfulness for at least 6 months.

WHAT WILL HAPPEN IF I VOLUNTEER?

Your participation is entirely voluntary. If you initially decide to take part, you can subsequently change your mind without difficulty. This will not affect your future treatment in any way. Furthermore, your doctor may decide to withdraw you from the study if he/she feels it is in your best interest.

If you agree to participate, you will be asked to participate in a recorded interview lasting up to one hour with one of the psychologists from [redacted]. This psychologist will not be your treating psychologist.

ARE THERE ANY BENEFITS FROM MY PARTICIPATION?

Through your participation you will be adding to our understanding of what role mindfulness may have with people who are receiving palliative care. In this way you will be contributing to the development of new knowledge within the fields of mindfulness, palliative care and psychology.

ARE THERE ANY RISKS INVOLVED IN PARTICIPATING?

Distress, fatigue or other symptoms are possible during the individual interview. You are encouraged to decline engaging or to terminate the interview at any stage.

WHAT HAPPENS IF I DO NOT AGREE TO PARTICIPATE?

If you decide not to participate in this study your treatment will not be affected in any way.

CONFIDENTIALITY

Your identity will remain fully anonymous. Your name will not be published or disclosed to anyone.

COMPENSATION

Your doctors are adequately insured by virtue of their participation in the Clinical Indemnity Scheme. The psychologists associated with this study are also covered by professional indemnity insurance.

WHO IS ORGANISING AND FUNDING THIS RESEARCH?

This study is organised and funded by the lead researcher, Mr. David Shannon.

HAS THIS STUDY BEEN REVIEWED BY AN ETHICS COMMITTEE?

The St. Vincent's Healthcare Group, Ethics and Medical Research Committee have reviewed and approved this study. This study has also been reviewed by the Research Ethics Committees at London Metropolitan University and [redacted]

CONTACT DETAILS

David Shannon, Senior Counselling Psychologist, Psychology Department, [redacted]
Tel: 01 [redacted]

RESEARCH PARTICIPANT'S RIGHTS

If you have any questions about your rights as a research participant, then you may contact:
[redacted] ppierce@olh.ie

Appendix F: Consent Form

PLEASE TICK YOUR RESPONSE IN THE APPROPRIATE BOX

- I have read and understood the Participant Information and Consent Form

  YES ☐ NO ☐

- I have had the opportunity to ask questions and discuss the study
  YES ☐ NO ☐

- I have received satisfactory answers to all my questions
  YES ☐ NO ☐

- I have received enough information about this study

  YES ☐ NO ☐

- I understand that I am free to withdraw from the study at any time without giving a reason and without this affecting my future medical care

  YES ☐ NO ☐

- I am aware of the potential risks, benefits and alternatives of this research study.

  YES ☐ NO ☐

- I consent to take part in this research study having been fully informed of the risks, benefits and alternatives.
  YES ☐ NO ☐

- I give informed consent to have my data processed as part of this research study.

  YES ☐ NO ☐

STORAGE & FUTURE USE OF INFORMATION:

- I give permission for material/data to be stored until transcribed and anonymised

  YES ☐ NO ☐

Participant's Signature: ____________________________________
Date: __________
Participant's Name (block capitals): ______________________

Investigator's Signature: __________________________________
Date: ___________
Investigator's Name (block capitals): ___________________

Appendix G: Distress Protocol

The following distress protocol has been devised in anticipation of any potential participant distress when engaging in the semi-structured interview process.
Although it is not expected that severe distress will occur, the protocol is included to assist in identifying and being responsive to any potential distress experienced by participants at any stage of the research process. As participants will all have a well-established mindfulness practice (as part of the inclusion criteria), this should mean participants already have good familiarity with managing distress and with the self-regulation of thoughts and emotions.

The distress protocol below has been constructed on the basis of Draucker, Martsolf and Poole's (2009) advice on the development of distress protocols for research concerning sensitive subjects.

Distress level

Mild indicators	Tearfulness Voice becomes choked with emotion/ difficulty speaking Participant becomes distracted/ restless
Action	Suggest a 'mindful' pause at this stage of the interview Ask participant if they are OK to continue? Ask participant if there is anything they need before continuing? Remind participant they can terminate the interview at any time Offer participant further time to compose themselves
Severe indicators	Uncontrollable crying, inability to talk coherently Participant experiences a panic episode e.g. hyperventilation/shaking Participant experiences intrusive thoughts/images e.g. flashbacks
Action	The researcher will stop the interview Express concern, empathy and reassurance The debrief will commence immediately Use mindfulness to acknowledge the distress and to calm and regulate breathing Accept and validate participant distress and suggest a follow-up meeting and to check-in by telephone the following day Record participant reaction in the patient's medical record Provide details of senior colleagues who can be contacted following the interview

Appendix H: Search Strategy #1. Exploring the effects of mindfulness in patients receiving palliative care

Concept 1	AND	Concept 2	AND	Concept 3
Mindful*		Palliat* OR End-of-life OR Hospice OR Life-limiting OR Life-threatening OR Comfort care OR Advanced disease OR Dying		Patients OR Dying

Appendix H: Search Strategy #2. Emotional distress in palliative care patients

Concept 1
Distress
OR
Psych*
Disorder*
OR
Symptom burden
OR
Illness burden

AND

Concept 2
Palliat*
OR
End-of-life
OR
Hospice
OR
Life-limiting
OR
Life-threatening
OR
Comfort care
OR
Advanced disease
OR
Dying

AND

Concept 3
Patients
OR
Dying

Appendix I: Example of development of individual participant themes (John)

Emergent Themes	**Transcript P.1.**	**Descriptive comments (Plain text)**	***Linguistic comments (Italicized text)***
	1. I: Can you say how it has been to practice mindfulness over the last number of months?		
Scepticism was a barrier initially; role of pre-existing attitudes in initial engagement is NB	2. E: How it has been to practice it over the last number of months? (Pause) I found that…in the beginning it was kinda a little bit difficult for me. Em, but over time… it became easier for me. Now when I say difficult I don't mean difficult to actually practice. I mean the concept of it rather than the actual practice of it. Em because I'd have been probably one of the 'nay-sayers' with regard to whether I would have thought it would be useful to me or not.	Difficult at the beginning Easier over time The concept of mindfulness rather than the practice Identifies self as initially a 'nay-sayer' in terms of its potential benefit Cautious	Is caution also being reflected in speech?
	3. I: So so you were cautious?		
	4. E: I would have been.		
	5. I: Yeah.		
	6. E: I would have been naturally a person that would have been, you know em, what's the best word to use, I suppose cautious or		
	7. I: Sceptical?		
Scepticism gave way to a calmness; a shift from the conceptual to the experiential over time; a reward from a willingness to engage despite scepticism; to suspend 'belief'	8. E: Sceptical yeah, yeah. Sceptical is probably a better word. Em, but over time I kinda found that that…it really gave me a… calmness. Now I wasn't looking for it to help with pain or and NAME had warned me that it's not something that's going to, you know, change the way you're your pain is but it might just help you	Sceptical With time it resulted in a 'calmness' Had been warned that it is not going to change pain but it might help as a coping strategy	Sceptical nonetheless implies an openness Time seems to be an important factor Interesting that 'pain' is introduced here (often spoken of as a synonym of 'palliative' care)
	9. I: Right		
	10. E: Deal with it		
	11. I: Right		

Emergent Themes	**Theme Clusters**	**Superordinate Themes**	**Page/Line**	**Key words**
Scepticism was a barrier initially; role of pre-existing attitudes in initial engagement is NB	Initial scepticism about engaging in mindfulness	Trusting experience	1/9	"I'd have been probably one of the 'nay-sayers' with regard to whether I would have thought it would be useful to me or not."
Has introduced something different into the domain of illness/ pain management	Has offered a new approach to pain management	New ways of being in relation to pain	2/2	"it's giving me something …different…em, and I actually feel as though I get a lot out of it."
A novel way to acknowledge the presence or absence of pain which makes it OK; regains sense of perspective/ control over pain			2/25	"at the end of a practice I kind of nearly always go, 'OK, I've pain there but it's OK"
Enables an experiential shift in relation to pain			3/1	"I think it just gives me a great kinda sense of …I suppose a bit of control over it."
Makes the recognition of pain more equanimous			3/22	"I can kind of say you know, 'I've pain there, that's fine. I've no pain there, that's fine."
Allows for the emergence of a sense of control in relation to pain			3/29	"I think it kind of gives me a little bit of control over it that maybe I hadn't had"
Offers an alternative focus to pain			4/1	"I'd have been one of those people that would focus on it [pain]."
Offers more choice about where/how attention is placed when pain is experienced – this is subtle			4/25	"it allows me a bit of control in the sense that it allows my mind not to focus on it"

Appendix J: Example of development of superordinate themes across participants

Identification of superordinate themes

Participant 1 (novice)	Participant 2 (novice)	Participant 3 (experienced)	Participant 4 (experienced)
Developing new ways of relating to pain	**Developing new ways of relating to pain**	**Developing new ways of relating to pain**	**Developing new ways of relating to pain**
Offers a sense of agency 4/25 “it allows me a bit of control in the sense that it allows my mind not to focus on it” 3/22 “I can kind of say you know, ‘I’ve pain there, that’s fine. I’ve no pain there, that’s fine.” **Alters medication use** 11/10 “I think I’m certainly using less… ‘break-through’ medication” **Restoration of self** 4/11 “I’M IN PAIN.”	**Offers a sense of agency** 4/27 “to see if I’m…actually feeling what I’m feeling” **Alters medication use** 5/29 “So I would actually say I would go without medication.” **The role of the breath** 2/3 “the breath is really important, where you place the breath and for me that’s…in the middle of my being and so it grounds me.” **Restoration of self** 21/16 “Just pain, just pain.”	**Offers a sense of agency** 7/21 “I suffer a lot of headaches so you can…sort of techniques to tease around the, you figure out not you’re not sore everywhere sort of thing…like that the pain is only in your head and only in certain parts of your head or whatever.” **Alters medication use** 9/15 “I did notice a definite definite change but…wasn’t sure just how much of it was timing of the cycle of the symptoms”	**Offers a sense of agency** 23/15 “‘I actually bring my awareness to that sensation and it does move, you know, it does, it shifts’” **The role of the breath** 22/20 “Well for that excruciating sharp pain you know I bring my awareness and I breathe” **Basis of acceptance** 21/20 “I’d say that is the foundation that it is giving me the ability to…accept and to ‘be with’ my limitations…physically.”