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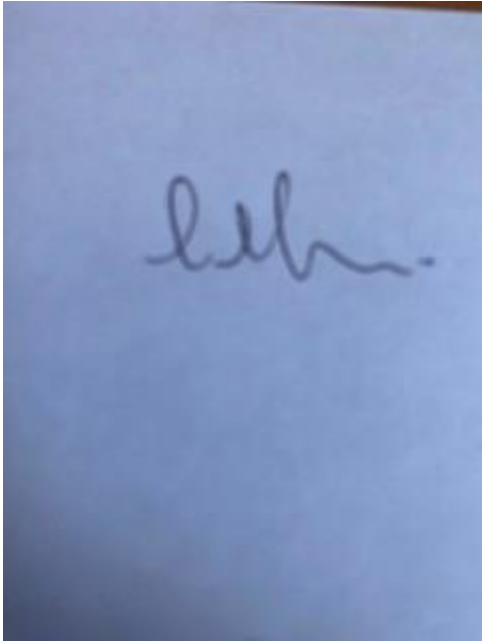
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Living Abundantly while dying: A Mindfulness-Based Intervention (MBI) for managing end-of-life anxiety.

Submitted by Lindsey Lister (19/08/23)

A dissertation presented in partial fulfillment of the requirements for the degree of MSc Studies in Mindfulness at the School of Education, University of Aberdeen.

I declare that this dissertation has been composed by myself; that it has not been accepted in any previous application for a degree, that the work of which it is a record has been done by myself, all quotations have been distinguished appropriately and the source of information specifically acknowledged.



Signature

Date 19 August 2023

Word Count 16,359 (excluding Abstract, Acknowledgements, Appendices and references)

Living Abundantly while dying: A Mindfulness-Based Intervention (MBI) for managing end-of-life anxiety.

Student: Lindsey Lister

Dissertation submitted in fulfillment of the Masters in Mindfulness Studies at the University of Aberdeen

Supervisor: Professor Graeme Nixon

“All the time I work with dying people and only a few of them know they are dying”

Sensei Koshin Paley Ellison

“In death, you are going to be what your experience is”

Joan Halifax

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Abstract

Living Abundantly while dying: A Mindfulness-Based Intervention (MBI) for managing end-of-life anxiety.

Background: Better health care has extended life expectancy and resulted in mortality becoming a taboo subject, leading to death anxiety. Palliative patients risk experiencing psychological and physiological distress. Treatments typically include medication that can cause onerous side effects. Complex symptomology can obstruct living well while dying. Mindfulness is emerging in palliative care as a non-pharmacological approach to managing symptoms. Education provides an opportunity for open dialogue around death and anxiety alleviation. Yet, there is no research on formalised death education programmes for palliative patients.

Research: This Integrative review aimed to synthesise the literature on the key considerations when designing an MBI to manage end-of-life anxiety. A multi-database search resulted in the critical appraisal of twenty-two papers that were a mix of theoretical and empirical literature.

Findings: Anxiety around death and dying may always persist. However, a combination of contemplative practices with formalised death education, including teaching how to manage palliative symptoms non-pharmacologically, may assist in promoting acceptance, resilience and ultimately, the ability to live well while dying.

Implications: The findings have contributed to creating a palliative care-specific MBI that addresses the gap in death education, including teaching from multidisciplinary health professionals on managing symptoms non-pharmacologically combined with adapted mindfulness and compassion practices.

Keywords: Palliative Care, Mindfulness-Based Intervention (MBI), Death education, Death Anxiety, End of Life Anxiety.

Glossary of Terms

The following is a list of common terms

Body Scan A mindfulness practice that requires the meditator to use focused attention to explore bodily Sensation.

Mindfulness Training of the mind to be aware of the present moment through practices such as the body scan.

Mindfulness-Based Intervention An approach to treat a medical condition using mindfulness practices

Meditation a practice that involves disciplined, focused attention on the breath or a mantra.

Paradigm A perspective, a way of viewing what is observed

Palliative care an approach taken to manage patients' physical and psychological, emotional, social and spiritual concerns at the end of life

Hospice Care a specific approach to managing holistic concerns associated with the end of life.

Patient: an individual receiving care or treatment from a clinical establishment

Death Anxiety a psychological and physiological response to the awareness of death.

Emotion regulation control of internal reactions to external events

Affect Dysregulation internal reaction that is exaggerated resulting in the closing down of logical thought processes

Settling the initial phase of a mindfulness practice where focused attention is used to calm the mind using counting or a mantra

Grounding the second stage of a mindfulness practice where the focus of attention is on bodily sensation.

Resting the third stage of mindfulness practice where there is open awareness of all experience (body, sound, hearing, sight, touch, smell).

List of Abbreviation

The following is a list of abbreviations that were used.

DA	Death Anxiety
MA	Mindfulness Association
MBI	Mindfulness-Based Intervention
MBLC	Mindfulness-Based Living Course
MBSR	Mindfulness-Based Stress Reduction
LWTDW	Living Well to Die Well
IR	Integrative Review
KI	Key Informant

Chapter 1 Introduction

1.1 Introduction

Approximately fifty-six million people require palliative care globally (World Health Organisation (WHO) 2023). In the United Kingdom (UK), current data suggest that 240 000 people become terminally ill annually (Petersdorff et al., 2021). Palliative patients risk experiencing psychological distress in the last year of life. Associated symptoms include mood disturbances, pain, fatigue, and cognitive impairment (Cancer Research UK, 2020, Singer, 2018). Treatments typically include medication that can cause physiological and psychological side effects onerous for the patient and financially burdensome for service providers.

The inspiration behind the desire to design a Mindfulness-Based Intervention (MBI) came from two experiences. The first was completing the Professional Enquiry assignment, which included the identification of several MBIs for potential use with palliative patients. The intention being to accommodate an array of palliative conditions; however, many identified studies focused on cancer. Also, experience working in a hospice has shown how palliative patients have illness and treatment-related issues that may make attending a standard course more challenging. The second experience was Living Well to Die Well (LWTDW), a course attended, created by the

Mindfulness Association (MA) (2023). It utilises mindfulness and compassion meditation practices to enrich personal well-being, which may result in dying well at end-of-life. The exploration of death and dying happened in a kind and compassionate way. The course prompted a renewed appreciation of a life well lived and assisted in developing resilience in challenging times.

Nairn et al. (2019) define mindfulness as 'Knowing what is happening while it is happening without preference'. Practising mindfulness and compassion may assist participants in gaining acceptance, one of the pillars of Mindfulness (Kabat-Zinn, 2013). With the acceptance of death, the patient may develop resilience, reducing the symptom burden, promoting empowerment, and reducing the need for pharmacological interventions.

National Health Service England has created objectives to improve palliative care for the next five years (National End of Life Care Partnership, 2021). The intention for this intervention appears consistent with meeting aspirations one:(personalised plans of care), three: (augmenting comfort and well-being) and five:(community is prepared to help) of the document.

Several challenges may obstruct the ability to perform research involving palliative patients, such as the increased risk of deterioration, short lifespan and the demands of other interventions and interactions that compete with patients' time and attention (Grossman et al, 2018). A literature review was considered appropriate for this enquiry as it allows the researcher to explore the available evidence without involving patients directly. The vast literature on death, dying, palliative care and mindfulness is acknowledged. The

methodological strategy for the literature review took the form of an integrative approach created by Whittemore and Knafl (2005). An Integrative review (IR) allows for the inclusion of both theoretical and experimental research, searched systematically and rigorously evaluated, resulting in a comprehensive understanding of the phenomenon studied (Whittemore and Knafl, 2005). Consequently, the aim was to review the literature to identify the key considerations when designing an MBI for palliative care patients to assist with death acceptance. The following key areas for exploration are.

- The taboos of Death and Dying
- Denial of Death by Modern Medicine
- The Secularisation of Death and Dying
- Palliative Care and Management of Distress
- Death Anxiety
- Dying Well

On completion of the literature review the findings will assist in providing answers that may inform the creation of an MBI yet to be realised in palliative care.

1.2 Death and dying: a taboo

Death and dying are not openly discussed in society (Doyle, 1999; Jolley, 2018; Marie Curie, 2017). Davies (2012), in his exploration into the importance of suffering, suggests that the wider community impacts behaviour; and equates suffering with primary and secondary problems. It could be argued that social conformity has an oppressive influence leading to aversion to exploring concerns held by the individual, which can manifest secondary issues. Davies (Ibid) suggests a lack of awareness of the primary problem, compounds the secondary issue. This publication helped gain insight into how the lack of opportunity to explore this critical phase of life is denied by making death and dying taboo subjects. The absence of a discussion creates fear around death and dying and a lack of opportunity to identify what is important in life. However, in his thesis, Walter (1991) explores death's taboo; suggesting that death is hidden, not forbidden. He cites media and medicine as dominant forces in the communication of death and how both associate dying with anxiety. The rise of medical interventions since the end of the Second World War resulted in lower mortality rates and more hospital deaths, contributing to the invisibility of death in society (Walter, 1991). This paper is over thirty years old, yet, arguably, Walter's assertions still have relevance today. Mannix (2018) does agree better healthcare systems mean people live longer, which has contributed to the denial of death and the existence of its taboo. Conversely, she directs

the cause toward the media; given Mannix's background as a palliative care doctor, this may have a bearing on her perspective.

1.3 Modern medicine's denial of death

The consensus is that a combination of technological advancement that keeps people alive at all costs, the belief in those technologies, along with evidence of the ability to extend life, obscures the division between life and death (Lehto and Stein, 2009); Dugdale, 2010; Seymour et al, 2010; Gawande, 2015). It could be suggested, that medicine is a victim of medical advancement. Gawande (2015) writes of his experience as a doctor; he suggests modern medicine is in denial, with the end of life seeming beyond recognition and the perceived failure being death. The National End-of-Life Care Partnership (2021) alludes to the existence of this mindset with the comment, *'It is important to emphasise that while death may not be a failure, but poor care is'* (Ambitions for Palliative and End of Life Care: A National Framework for local action 2021 to 2026, p6). Bernacki et al. (2014) argue that clinicians will opt for life-sustaining treatment unless the patient states otherwise. With firsthand experience in palliative care, this notion is challenged by acknowledging limits in sustaining life with clinicians guiding patients toward death acceptance. The sources from which the points originate were considered anecdotal, but valid as the contributors have medical backgrounds, and may be representative of medical culture. Conversely, there is a cultural shift with the need to be open about death and dying, which has prompted the introduction of death cafes (Impermanence, 2023), designated areas where death is publicly discussed. Campaigns such as dying matters (Hospice UK, 2023) also promote open discussion.

1.4 Secularisation of Death

Historically social discourse around death and dying was placed with the church and organised religions (Walter, 1991). Consequently, the acceleration of secularisation prompted other groups to adopt the death education role (Dugdale, 2010). Secularism is the belief that religion is not the governing principle under which society operates (Arthur, 2009). Acknowledging the perceived lack of preparation by faith communities prompted phenomenological research into participants' experiences of a project entitled Living Well in the End Times (LWET) (Slater and Collicutt 2018). The programme provided parishioners of a Christian faith community an opportunity to reflect on death and its meaning. The findings identified six themes, which included a recognised need to explore death and dying issues and the value of sharing experiences with empathic peers. Unfortunately, this study's brief account of data collection may weaken the findings' reliability (Hammersley, 1987). Walter (2015) argues that the church is no longer an authority on dying, which was alluded to by the study's authors who suggested the clergy trained to facilitate the LWET course lacked confidence in approaching the subject with parishioners.

It could be argued that the palliative care movement has replaced religion in advocating a dialogue around death and dying by acknowledging the associated suffering. The field of Thanatology acknowledges this view (Fonseca and Testoni, 2012; Corr et al, 2016; Chapple et al, 2017), with a branch of science devoted to death and dying.

Arguably, the creation of Thanatology resulted from replacing religion with secularisation, and the acknowledgement of death avoidance created by the scientific community. Corr (2016), in his exploration of death education acknowledges the value of preparing individuals for death and explores critical aspects of death and dying. This paper was valued for its identification of core themes around living well to die well, which included common humanity and associated meaning and purpose with quality of life considered relevant for professionals. It could be asserted that secularisation has precipitated distress in palliative patients, and hospice care is secularised and risks reinforcing this suffering if existential issues are unaddressed. Literature exploring death education refers to the importance of informing children, the elderly and health professionals (Fonseca and Testoni, 2012; Chapple et al, 2017), with no acknowledgement of terminally ill patients, considered most deserving of death education. This realisation, coupled with the findings presented by Slater and Collicutt. (2018), reinforces the need for death education, specifically for palliative patients.

1.5 Palliative Care and the management of distress.

'Total Pain' was coined by Cicely Saunders, the hospice movement founder (Clark, 1999). *Total pain* is defined as pain of a complex nature, not just physical, but encompasses emotional, social, psychological, and spiritual elements, unresponsive to pharmacological and therapeutic intervention (Mehta and Chan, 2008). Hospice care takes a holistic approach because of symptoms such as total pain. Streeck's thesis on distress and dying suggests a 'taboo of suffering' in palliative care (Streeck, 2020). She argues clinicians are at risk of eliminating suffering and, ultimately, the sufferer by terminal sedation when the patient's distress is perceived as intolerable and

unmanageable. Arguably, Streek's standpoint appears controversial; nevertheless, she makes the case that some patients may wish to tolerate distress for personal reasons, which should be their choice. Varelius (2019), in his paper about end-of-life distress, suggests that suffering can be part of dying well. Alleviating all distress would deny the opportunity to address practical matters such as making a will, existential concerns regarding the meaning of a life lived, and, alleviating suffering may separate the self from reality. Davies (2012) posits distinguishing between adaptive and maladaptive suffering is essential. Moreover, some would suggest that suffering is pathologised and emotions such as grief, anger, and sadness should be recognised as an indication that life will end and should be allowed expression (Hartogh 2017). All perspectives are acknowledged, but what constitutes productive and unproductive suffering is a matter of perspective.

1.6 Death Anxiety (DA)

Simon defines DA as 'anxiety related to the awareness of death' (Simon, 2014, p1). Grossman et al. (2018) elaborate further by suggesting DA relates to the concern triggered by knowing death exists and the realisation that death is absolute, with the cessation of the self. A mixed-methods correlational study into death anxiety and cancer patients found a positive correlation between anxiety and what will occur once dead. DA is associated with shorter life expectancy and higher pain scores; the study findings provide empirical evidence that anxiety exists with the cessation of self at the end of life. The findings were not generalisable to a UK population as the seventy study participants were predominantly Turkish with cancer diagnoses.

Mannix (2018) describes an account of a palliative patient concerned about the act of dying and how acknowledging those fears precipitated a conversation about the dying process. Consequently, this discussion allayed the patient's fears and worries. Although anecdotal, it does highlight that the existence of fear of the unknown (the active process of dying) was distressing for this patient. Experience of working in palliative care has included witnessing these conversations and validating Mannix's account as typical in a hospice setting. A literature review into fears around death, anxiety and re-experiencing cancer undertaken by Sharpe et al. (2018) identified anticipatory concerns around the process of dying associated with DA. Simon (2014) suggests DA is not always considered obstructive but could be beneficial in providing an opportunity to reframe concepts around meaning and purpose. A systematic review of quantitative studies by Grossman et al. (2018) into interventions for advanced cancer patients with DA identified nine studies that met their inclusion criteria. The study's findings identified two main categories of intervention: meaning based and dignity related. Psychotherapy-based interventions that explored spirituality and existential matters were seen to promote meaning and purpose. The review's limitations included the exclusivity of cancer patients, and that inclusion of quantitative studies only provided a limited report of intervention benefits; the therapies were psychotherapeutic, and subjective reports would have deepened the analysis. Yet, this paper provided insight into how meaning-making interventions appear beneficial in managing DA and support an adapted LWTDW course specific to palliative care.

1.7 Dying Well

Given that the MBI could promote dying well, available research may provide evidence of what elements are essential to a good death. A literature review of thirty-six critically appraised studies identified eight main themes, including emotional well-being, spirituality and quality of life. Thirty-four subthemes included the opportunity to discuss mortality and its meaning, death acceptance and social connection (Meier et al, 2016). The review helped identify patients' wishes and supported the creation of the MBI. Since this is a qualitative review, declaration of study limitations, including a section on researcher bias, may have strengthened the finding's trustworthiness. The review incorporated papers from the UK, which made the findings generalisable to a local population.

In contrast, Heyse-Moore (1996) added a further dimension to what could contribute to dying well in their paper on spiritual pain in dying patients. They acknowledge meaning-making as necessary in coming to terms with a terminal illness but also identify other vital aspects that are associated with the adapted LWTDW course. They included prioritising what is essential when actively dying, speaking personal truth in a safe, non-judgmental environment, guided imagery and finding the good in present-moment experiences. Mindfulness in its secularised form and a key aspect of the LWTDW course, has links with spirituality with its roots in Buddhism (Kabat-Zinn, 2003). The paper is considered anecdotal, as Heyse-Moore uses clinical experiences as a palliative care doctor to explore this subject. However, due to the significant experience of Heyes-Moore his/her insight added value to the research and supported the creation of this unique MBI for palliative patients.

1.8 The emergence of Mindfulness in the Palliative Care Field

In the last 20 years, attention has turned toward non-pharmacological approaches to managing the symptoms associated with a palliative illness (Hokka and Polkki al,2014; Coehlo et al, 2017; Mochamat et al, 2021;). A meta-analysis of systematic reviews of non-pharmacological interventions undertaken by Duncan et al. (2017) identified twenty-one papers that met their inclusion criteria. MBIs were regarded as behavioural interventions, and Mindfulness-Based Stress Reduction (MBSR) was considered an efficacious alternative to pharmacology. However, the meta-analysis identified was specific to breast cancer patients, which means findings are not generalisable. Of the papers identified for the Professional Enquiry assignment, the findings identified benefits in managing psychological distress in cancer and palliative populations (Carlson et al, 2016; Poletti et al, 2019; Zimmerman et al, 2020). Conversely, a systematic review by Latorraca et al. (2017) and a later metanalysis undertaken by Cillesen et al. (2019) suggested the benefit was marginal. The evidence suggests MBIs have limited effect. Still, it is evidence that it can be of benefit in palliative care and should be considered as another non-pharmacological therapeutic intervention that may have the potential to promote comfort at end-of-life

1.9 Key Informant (KI)

A health professional specialising in palliative care was consulted to discuss the new MBI structure and content. They have experience of teaching mindfulness and have created an MBI for fatigue management. They argue that health professionals who actively practice and teach mindfulness are uniquely positioned compared with other course creators, as they have clinical insight into palliative symptomology and are suitably qualified to create a palliative specific MBI. The KI suggested the adapted LWTDW course should focus on symptom

management, not just end-of-life anxiety; that a comprehensive approach will result in patients living well while dying. Their argument had validity, and palliative symptomology was considered in the creation of the MBI.

Chapter 2 Methods

2.1 Research Approach

Aveyard (2007) suggests a literature review is essential as the intention was to examine available subject-specific literature, which is analysed, synthesised and outlined in a report. On reflection, a well-orchestrated literature review could save time clinically. Also, single studies reviewed in isolation may have less value, whereas appraisal of multiple papers specific to a research area will add weight. However, distinctions are made between a research background which justifies the research question (Snyder, 2019) and a literature review as a methodology. Snyder (Ibid) suggests it is a process which incorporates specific stages to ensure the review is valid and reliable. After reading a narrative review by Bernacki et al. (2014), discernable differences were identified between a systematic and narrative review. The narrative review presented the research findings with no evidence of assessment of rigour. Although the review was informative, a lack of rigorous evaluation affected the review's perceived value. Randolph et al. (2009) suggest that narrative reviews are susceptible to researcher bias.

An Integrative Review (IR) was considered appropriate, as the combination of explorative and theoretical research, informed the structure and content of this new intervention yet to be realised in palliative care. Theoretical reports may provide insights from individuals in related fields not considered before, creating an extensive exploration. Knafl and Whitmore (2005) suggest that a skillfully performed IR will be relevant in

practice while theoretically shaping established knowledge about a phenomenon. Unlike a narrative review, research is evaluated for methodological rigour.

The research paradigm from which the research approach correlates is Interpretivism. This investigation was focused on the subjective experience of the patient group studied. Interpretivism involves seeking to understand a phenomenon through human experience, which is complex and unpredictable, specific to the circumstance as it happens (Parahoo, 2006). Randolph et al. (2009) suggest that it would appear coherent if a qualitative review adopted a subjective perspective, with consideration of personal bias, and its influence on the study and reflected in the review. Cooper (1988) argues that achieving a neutral approach is debatable, and care should be taken to give opposing evidence fairly without sacrificing personal standing on a specific subject. A systematic approach for assessing and synthesising the evidence can minimise bias, although researchers must be aware of their own susceptibility to bias. The author supports mindfulness and could inadvertently select favourable evidence for inclusion. Snyder (2019) suggests that a lack of understanding of what the studies communicate could result in unsound claims. Critical Appraisal Skills Programme (CASP, 2022) provided guidance on appraising selected studies, as did guidelines provided by Crombie (1996). These tools assist in the evaluation of the strengths and limitations of included literature in the context of this research.

In addition to critically appraising the research, in-depth knowledge of specific criteria for mindfulness research was also essential. Van Dam et al. (2018) highlighted the methodological concerns that must be considered when

assessing MBI research. The article suggests that researchers of empirical studies are responsible for declaring any potential side effects from an MBI. They also provide a valuable guide to consider when appraising MBI research. On reflection, it can be a case of reading between the lines, being aware of what might be concealed. Consideration was given to evaluating theoretical reports; this was performed using the stepwise approach to theory analysis introduced by Walker and Coalson (2011). Internal and external validity, factors that can influence the research outcome and level of confidence in the findings (Parahoo, 2006) were also considered. Regarding internal validity, completion of the LWTDW course resulted in insider knowledge of the course, and its content. Firsthand experience of the course assisted in deciding what was to be included in the palliative care specific MBI. Moreover, external validity; the extent to which the research findings are generalisable to the population being studied (Chittaranjan 2018). There was no certainty regarding the relevance of the chosen literature included in the research reflected the characteristics and settings of a local palliative population, which could lessen the validity of the findings.

2.2 Research Question

The research aim was to Identify themes in the identified literature that would contribute to answering the following question;

What are the key considerations when designing a Mindfulness-Based Intervention for Palliative Care Patients to Manage end-of-life anxiety?

2.3 Search strategy

The following MeSH terms were included in the literature search.

Mindfulness: training of the mind to be aware of the present moment through practices such as the body scan.

Meditation: a practice that involves disciplined, focused attention on the breath or a mantra.

Death Anxiety: a psychological and physiological response to the awareness of death.

Fear of Death: an emotional response to the awareness of death.

Palliative care: an approach taken to manage patients' physical and psychological, emotional, social and spiritual concerns at the end of life

Hospice Care: a specific approach to managing holistic concerns associated with the end of life.

Patient: an individual receiving care or treatment from a clinical establishment

Given the paradigm of Interpretivism, a qualitative tool using the acronym PICO (Population, Issue, Context, Outcome) was utilised and informed the MESH choice, identifying predominantly qualitative research. Search terms were considered; definitions were provided to create transparency and strengthen the review's reliability. Including both 'meditation' and 'mindfulness' which may have increased the yield of results, as mindfulness is a form of meditation. Exact phrases such as 'death anxiety'; were used. Experience of searching including just 'anxiety' resulted in an overwhelming number of results. Using the exact phrase 'death anxiety' did narrow the results to pertinent papers. The decision to include 'hospice care' was taken through discussion with the university librarian, as they suggested in certain countries, such as the United States (US), palliative care is known as hospice care, which may have increased search results.

Boolean operators 'AND' 'OR' and 'NOT' promote an efficient search (Ebsco Connect.Com,2022). Studies focused on caregivers, professionals and children/adolescents, and empirical studies not presented in English were excluded.

The following search strategy identified relevant results.

Mindfulness OR Meditation AND 'Death Anxiety' OR 'Fear of Death' AND palliative Care OR 'hospice care' AND patient.

The following databases identified relevant empirical and theoretical papers: Primo, Scopus, Web of Science and Google Scholar. Primo is the electronic database associated with the University of Aberdeen that includes

published works in the form of books, articles and course materials (Borompoka 2022). This database yielded twenty-six thousand one hundred and twenty-five results; therefore, due to the sheer volume, subject headings were restricted to just mindfulness, significantly reducing results to seventeen thousand. Scanning titles and abstracts for the first one hundred results identified three relevant papers. *Scopus* is a recognised database with articles for multiple disciplines rigorously evaluated (Elsevier, 2022). Three of the ninety-six results appeared appropriate but were discarded after reading the abstracts. Web of Science is another multidisciplinary database. Considered one of the first known databases frequently used to identify research (Birkle et al, 2020), it yielded nine hundred and sixty results. After scanning titles and abstracts, thirty-three appeared promising but were not specific to DA. Google Scholar, a database available for generalised access, provided a comprehensive literature search. Aveyard et al. (2016) suggest avoiding Google Scholar due to the risk of uncovering many irrelevant results. Nonetheless, exploring identified titles and abstracts revealed a diverse collection of papers unidentified by the other databases, which included a couple of thesis reports that provided texture. One hundred and three results were reduced to ninety-one considered relevant and further reduced to twenty selected papers. Only one duplicated paper was identified in Primo.

2.4 Inclusion and Exclusion Criteria

Since the literature review contributed to the creation of an MBI unique to palliative care, no limitations were placed on the date of publication. Included literature was limited to the English language. Literary texts specific to adult patients were included, literature focusing solely on children and carers was excluded.

2.5 Ethics

Suri (2020) explored the ethical considerations of performing a systematic review, this paper highlighted the importance of considering non-maleficence at every step of the research process. Even though patients are not directly involved, the researcher needs to consider harm reduction including judgement of methodology and validity of the findings and how they may impact on the patient group under study. Although the research does not require direct patient involvement, but may involve patients as a constructed intervention, ergo in line with BERA (British Educational Research Association, 2018) ethics approval was sought from parties connected with the University of Aberdeen in the research proposal stage, the application form for ethics approval is included in the appendix (Appendix A).

2.7 Data Collection

Initially, a thorough approach to literature searching was chosen; identifying all literature related to the project was considered significant. Aveyard et al. (2016) suggest that an exhaustive search reduces the risk of bias as all evidence is appraised and included. Due to the immensity of available evidence identified through database

searching a purposive search of the literature was opted for instead; a selection of papers was identified that met the review requirements. Although Aveyard et al. (ibid) acknowledge that selective searching may increase bias, thus invalidating research, they recognise that purposive or selective sampling aligns with an interpretive approach, as critical themes can arise from the search results. Arguably, the chosen papers added clarification that the MBI was warranted, provided depth of understanding regarding patients' experiences and needs, and generated ideas that informed the MBI content and design.

The most relevant papers were identified by reading the titles and abstracts. Each paper was read through to confirm inclusion; with certain literature excluded as considered irrelevant. Each article was summarised leading to the identification of four main themes;

1. The role of spirituality in palliative care
2. Mindfulness-Based Interventions and palliative care
3. Approaches to the cultivation of acceptance of death and dying
4. Mindfulness and compassion practices that could help manage death anxiety

Chapter 3 Data analysis

The data analysis approach was inductive; themes, relationships and patterns were identified from the data, which is synonymous with an integrative approach (Aveyard et al, 2016). For each theme, identified literature is presented in table form (see appendices). The intention was to focus on the patients' experiences which required a qualitative data analysis. However, multiple selected papers were quantitative and unanticipated. On reflection, inclusion of quantitative studies was considered valuable as they provided data on causation: the effect and impact of interventions (Parahoo, 2006). Sadan (2014) suggests that a mix of methods can be connective and provided a comprehensive analysis of the research area. The research question allowed for some flexibility with qualitative data providing insight into what may be experienced by patients participating in a spiritual endeavour such as mindfulness which is predominantly qualitative and the focus of themes one and two, and inclusion of quantitative studies which informed what will be included in the MBI that dominated themes three and four.

3.1 The role of spirituality in palliative care

The exploration into spirituality commenced with a definition. Puchalski et al. (2009, p887) define spirituality as *“the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant and sacred”*. Some would suggest spirituality is synonymous with religion (Bregman, 2004; Hardy,1998), including the above definition provided clarity as to

how spirituality is defined regarding this research. Evidence suggests spirituality and religion are clearly distinct, that a person can be spiritual but not religious; meaning they are unaffiliated with a particular system of denomination or devotion (Saucier et al., 2006). Mindfulness in Western culture is secularised and not affiliated with any religion (Purser, 2016).

Cross-sectional research by Hardy (1998) provided empirical evidence to suggest that the presence of spirituality influences the acceptance of death. It considered the impact of spirituality on anxiety associated with mortality and dying palliative care patients. The findings of two questionnaires completed by fifteen participants identified a positive correlation between high spirituality and low DA (Appendix B). Comparative studies could substantiate the research claims, no identifiable studies indicated a gap in the research. Several limitations were noted; the sample was purposive; in this instance, convenience sampling was used. Some would suggest this introduces bias as participants may have voluntarily participated in the research and be opinionated towards spirituality (Sousa et al, 2004), resulting in findings that are unrepresentative of a wider palliative population. Dawson (2009) suggests convenience sampling is utilised when the researcher is time and resources restricted, which could be suggested was the rationale behind why this sampling frame was adopted, as the research stated Hardy was working toward her master's degree in social work (Hardy, 1998). The sample population was small; a power calculation performed in the research planning stage could have assisted in identifying the quantity of participants needed to prevent misleading findings (Jones et al, 2003), which weakened the finding's validity. Also, in some instances, carers assisted in completing the questionnaires, which may have also invalidated the

findings. The reading of questions, whereby certain words could be emphasised, may have introduced bias, influencing the participants' responses. Hardy (ibid) also reported that participants stated that completing the questionnaires depleted their energy; this could suggest fatigue associated with a terminal condition impaired the ability to answer questions accurately, further invalidating the study findings. Despite several limitations identified, the research had value in suggesting spirituality may be a buffer against DA in palliative patients.

The investigation by Hardy (1998) suggested spirituality could positively influence the death perception in palliative patients, resulting in the consideration of its influence on how palliative care is received.

Chaiviboontham (2015) undertook a cross-sectional study on what elements must be present for effective palliative care. Again, no other comparative study indicated a gap in the research. The findings suggest that spirituality is critical to adequate palliative care (Appendix B). The sample population was more significant at two hundred and forty participants compared with that of Hardy (1998), strengthening the finding's reliability and validity. The researcher did pilot the questionnaires before the study to assess whether they were workable with the study population, which was lacking in the research conducted by Hardy (ibid). Most of the study participants were Buddhist and unrepresentative of broader palliative populations who may be secular, spiritual, or religious. Whereas the study conducted by Hardy (ibid) had increased scope regarding generalisability as she differentiates spirituality from religion. The author suggests a purposive sampling weakened the reliability of the findings. Inclusion of data about those who chose not to participate, and their reasons why would have provided transparency and strengthened the finding's validity. Also, there were no mention of how participants were

approached (i.e., consent to participate), and the researcher may have influenced the participant's answers through reading the questions to participants; both aspects may influence the answers and invalidate the findings. This paper, considered in isolation, is of limited value due to the lack of generalisability regarding the study population and their religious affiliation; however, considering the findings with those presented by Hardy (ibid) strengthens the support for spirituality in a palliative care environment. The study findings support spirituality and palliative care and led to consideration of patients' experience.

The narrative review performed by Yosep et al. (2022) provided a general overview of the spiritual needs of palliative care patients. Ten studies met the inclusion criteria, identifying four key themes (Appendix B). Even though the researchers mention that they assessed for quality using recognised assessment tools, it could be suggested that lack of appraisal of included literature limits its value. Given that the participants of the included studies were not from the UK, this limits the finding's generalisability to a local palliative population. However, the review provided insight into how spirituality can significantly impact the lives of palliative patients.

Comparing the study findings with the content presented in the opinion paper by Rake-Marona (2018), similar themes were identified (table one). Even though the content is anecdotal, it was valued because Rake-Marona (ibid) has over twenty years of pastoral experience working with dying patients. The paper highlighted how letting go could bring new ways of relating to significant others and how legacy: the lasting contribution to the next generation, can bring comfort. Compared to the previous study, a strength of this paper is that the patient encounters were not solely associated with cancer, making it more inclusive of the palliative care population.

Yet, it was considered weak due to the lack of generalisability to a local palliative care population, as Rake-Marona (ibid) and the patients she encountered were American. Limitations of both papers are acknowledged but considered relevant in highlighting the beneficial contribution of spirituality in the lives of palliative patients. The last two papers were qualitative studies with similar methodological approaches to the patient's experience of spirituality in palliative care. Nakashima and Canda (2005) utilised semi-structured interviews to gain insight into the experiences of sixteen elderly palliative participants (65-103 years of age). Mok et al. (2010) utilised a phenomenological interpretive approach, interviewing participants to understand spirituality and spiritual care for this population. Both studies employed purposive sampling strategies for participant recruitment. It could be suggested Nakashima and Canda (2005) used critical case sampling: selected participants were chosen because they were seen to possess the characteristic of resiliency (Johnson et al, 2020). Whereas Mok et al. (2010) approached sampling through data saturation, they discontinued sampling once they had collected enough data. Fusch and Ness (2015) suggest data saturation is reached when no new themes and coding are identified, emphasising lots of rich data: the quality of the phenomena being studied as opposed to thick data, the amount gathered. The author argues that the approach taken by Nakashima and Canda (2005) strengthens trustworthiness and dependability, by assessing for participant resiliency using Missoula-VITAS Quality of Life Scale, a robust palliative specific assessment tool (Byock and Merriman, 1998) by both researchers and hospice clinicians. Conversely, it could be suggested the approach taken by Mok et al. (2010) also considered

dependability as participant recruitment and data collection took nine months to complete and ceased on achievement of data saturation.

Mok et al. (ibid) did consider confirmability; in the form of triangulation, which included participant and caregiver interviews and field notes. Arguably, there needed to be more data on the audit trail, which is clearly stated in the study performed by Nakashima and Canda (2005). An audit trail can provide a basis for the reader to judge whether the research is reliable, as the researchers' reasoning can be followed (Carcary, 2009). Johnson et al. (2020) suggest peer review is characteristic of rigour as the assessment of the stepwise approach to data collection is performed by an independent researcher, thus reducing the level of bias, which strengthened the confirmability of the findings. Confirmability was also impaired as no further participant contact occurred following the interviews. Since participants were palliative and data collection took nine months, disease progression may have made conferring with participants challenging. It could be suggested a level of transparency was created by the researchers by reporting the study's limitations. Whereas Nakashima and Canda (2005) mentioned they had been able to confer with participants. Mok et al (2010) discussed reflexivity: whereby the researchers consider how their background/ perspective may influence the research and data analysis, thus reducing researcher bias and strengthening the findings' confirmability, which was lacking in the methodology of Nakashima and Canda (2005). Although transferability is limited when considering a UK palliative population, the findings presented by Nakashima et al. (ibid) may be more representative of a palliative care community, as Mok et al (2010) focused specifically on cancer patients. Both studies presented

methodological weaknesses, yet uncovered themes identified in previous papers appraised (table one), which could be argued provides weight regarding evidence for this current investigation.

3.2 Mindfulness-Based interventions and Palliative Care

The emergence of mindfulness, as discussed on page fourteen referred to a systematic review (Latorraca et al, 2017) and metanalysis (Cillesen et al, 2019). Both papers suggested mindfulness was marginally effective for this patient population (Cillesen et al, ibid). With findings of a small number of studies considered statistically significant but have a high risk of bias (Latorraca et al, 2017). An advantage of a systematic review and meta-analysis is that a wide range of published data on the same subject is appraised and assessed for methodological quality, saving time for those seeking evidence-based solutions. Effect size is calculated and adjusted with an assessment of bias and heterogeneity (level of diversity), which the author argues strengthens the validity and reliability of the findings. However, systematic reviews traditionally review Randomised Controlled Trials (RCT). RCTs are ranked higher empirically (Evans, 2003); it could be asserted they provide the most reliable findings when judging the impact of an intervention by comparing it with a control, potentially minimising the risk of error. Although, some would suggest that RCTs assess the effects of one episode of an intervention that may only be five minutes long (Guan et al, 2021), which dismisses other markers of effect. It is understood that the effect of mindfulness can occur incrementally over more extended periods neurologically and psychologically (Carlson et al., 2016), suggesting that qualitative or mixed methodologies are more appropriate, as mindfulness

is a subjective experiential experience and a valid approach to capturing meaningful data. The included studies for appraisal are a mix of qualitative and mixed methods.

The first two studies used qualitative methodologies to explore the potential impact of mindfulness on palliative patients. Zimmerman et al. (2020) explored the feasibility of a unique MBI for advanced cancer patients. The paper focused on the qualitative element of a more extensive mixed-methods study. Twenty participants were interviewed pre- and post-intervention, and discourse was analysed to identify themes and patterns appropriate to a qualitative methodology. The study findings (Appendix C), which included reducing anxiety, indicated effects could be experienced rapidly and considered valuable when palliative patients have short life expectancies. Shannon (2020) explored the experiences of four palliative participants who practice mindfulness and its effects on their symptoms. The study findings (table two) indicated that the participants developed an ability to regulate emotions. Evidence suggests “affect dysregulation” is a key aspect of anxiety disorders and that “emotion regulation” may assist in alleviating anxiety (Hoffman et al, 2012). Shannon used an Interpretive Phenomenological Approach (IPA); this methodology allows the researchers to interpret and make sense of the participants' lived experiences (Cresswell, 2007). It could be suggested Zimmerman et al. (2020) approached transcript analysis more robustly by utilising computer software programming for coding themes. Along with employing two researchers who independently read through transcripts and had regular meetings to reach a consensus on the data (Cresswell and Cresswell,2018). However, given the nature of IPA research, the researcher and participants are co-researchers, with the researcher interpreting the participants' lived experiences. The

author suggests there was no requirement for triangulation: cross-validation of the findings (Parahoo, 2006), but the emphasis was on reflexivity and transparency in robustly describing data collection and analysis. Shannon (2020) provided a reflexivity statement about his background, which included experience in palliative care and mindfulness; this was also seen as a limitation as Shannon (ibid) could inadvertently introduce researcher bias; by interpreting the findings overly optimistically to persuade the reader into favouring the findings, thus weakening credibility.

Zimmerman et al. (2020) considered ethical considerations, which included anonymising participants, after gaining voluntary consent and ethics committee approval, but provided no detail on data storage or reflexivity. Researchers did not discuss how they may have influenced participants' responses which could affect the trustworthiness of the findings. The participants knew the study was part of work towards a PhD, which could have influenced their responses. Shannon (2020) did, however, consider Demand Characteristics, the cues participants pick up from the researcher, which can inadvertently influence participants' responses (Nichols and Maner, 2008); this was monitored through regular discussion with an associate experienced in IPA which the author suggests strengthens the credibility of the findings. There was no mention of whether participants were invited to read transcripts in the work of Zimmerman et al.(2020), which weakens the findings' confirmability, as confirmation of transcript accuracy strengthens trustworthiness. It could be suggested results of both studies are not transferable to broader populations as participants had a cancer diagnosis; however, examining the characteristics of both sets of study participants aside from geographics (Appendix C), they correlate with those

encountered locally. Both studies were considered valuable, with potentially meaningful improvements to quality of life that could be sustained with regular practice.

Polletti et al. (2019) undertook a mixed methods study into the impact of MBSR on twenty early-stage palliative patients. The study findings (table two) included the development of the ability to manage anxiety. Polletti et al. (ibid) utilised the Karnofsky Scale (Karnofsky, 1949) to assess participant's performance status; which could be suggested strengthens the study's dependability and credibility as it is a recognised assessment tool used in oncology (Catlin et al, 2014). Also, from clinical experience, this tool is used to assess patients' phases of illness. The author suggests a probability value of 0.75 is not a significant marker of benefit regarding effectiveness in controlling pain as stated in the abstract, whereas a threshold of 0.05 is considered a marker of statistical significance (Dahiru, 2008). Small sample size is a factor contributing to this result. Arguably, it could be suggested mindfulness may not reduce pain but assist in providing a coping mechanism for approaching pain. Polletti et al (2019) considered triangulation as they referred to participant's and researcher's diaries along with audio recordings, to strengthen the findings' confirmability (Johnson et al, 2020). It could be suggested the trustworthiness of the findings was strengthened by including a reliability check, which included the questions asked of participants and details regarding how data was analysed, which was rated higher regarding dependability than Zimmerman et al. (2020). Transferability is considered low, as with the study undertaken by Zimmerman et al. (ibid) and Shannon (2020); the participants were Italian and diagnosed with cancer. The study was considered valuable in that mindfulness enhanced the person-centred approach to their care and assisted

patients in becoming attuned with their bodies which helped promote calm in coping with cancer. Group-based interventions were of interest as the adapted MBI would incorporate a group approach, which was explored in the final paper on this theme.

Chadwick et al. (2008) performed an IPA to explore four patients' experiences of a mindfulness group intervention. Of the seven themes identified in the findings (Appendix C), the group process assisted participants in promoting acceptance of their terminal illness through interacting with fellow participants. There was no comparative study available or complete research associated with researchers identifying a gap in the literature. Freedland (2020) suggests one possibility that research projects do not progress to complete research is because the pilot study may answer the research question. In this instance, the research demonstrated that a group-based MBI is feasible for palliative care populations and that the richness of the experience was captured. However, with no other comparable research, the value of the findings did have limitations as they are specific to the participants studied.

The research was considered valuable as the findings did provide insight into the potential benefits of a group MBI with terminally ill participants. However, detail was lacking regarding how participants were recruited, which weakened the study's dependability. It could be argued that evidence of transparency increased the finding's trustworthiness by including positive and negative comments from the participants who volunteered to participate in the research. Comparing approaches to IPA with that of Shannon (2020). It could be suggested

credibility and confirmability are strengthened with the data analysis procedures considered more robust, with the inclusion of a researcher inexperienced in mindfulness who initially analysed. The author suggests that multiple researcher involvement strengthens confirmability as researchers can work independently to analyse data and can arrive at a consensus on the findings through meetings to discuss the research (Sweeney et al, 2013). Although, reflexivity is lacking as there is no mention of how the researchers may have influenced the research process and data analysis. Ethically the research is comparable to that of Shannon (2020) and considered a marker of robustness in research (Tracy, 2010). Participants' well-being was regarded throughout the intervention, which according to Van Dam et al. (2018), is an essential consideration when undertaking MBI research because of the potential occurrence of ill effects. Conversely, approaches to participant wellbeing were lacking in both studies by Polletti et al. (2019) and Zimmerman et al. (2020) which discredits both studies. However, the study findings were transferable to a local palliative population, which was considered a strength. As a group of studies, they were considered valuable experientially in that mindfulness may help manage DA and was worth pursuing as an intervention. The next theme may provide further insight into death and dying acceptance from a different perspective.

3.3 Approaches to the cultivation of acceptance of death and dying

The literature identified for this theme had a commonality: Buddhism. It could be argued dying and death are inevitable and an accepted belief by the Buddhist community (Nairn, 2004; Halifax, 2008; Holmes, 2017; Khyentse, 2020). As His Holiness the Dalai Lama (2008) suggests accepting the existence of one's demise opens

the opportunity to cultivate approaches to lessening the distress associated with death and dying. In the acceptance of death, one may live well. This notion has contributed to shared wisdom and subsequently published literature on the subject.

Michaud's (2020) thesis discusses how complex death anxiety is, how it manifests and the notion of impermanence; the knowledge that change is inevitable which is central to whether one's demise can be accepted. She includes approaches to DA through Buddhist teachings supported by empirical research. Considering its relevance, comparing this paper with the narrative review presented by Yosep et al. (2022) on page twenty-two, there is no mention of an assessment of the validity of any of the included sources, therefore the accuracy of the sources may be questionable.

Arguably, this has little value empirically when considering the hierarchy of evidence (Evans, 2003) and could be considered lower than a narrative review but higher than expert knowledge, such as the paper by Rake-Morona (2018) presented on page twenty-three. Generalisability of this paper in relation to DA was considered, it could be argued that the subject is universal, as death is part of the human experience. This paper had relevance as Michaud (2020) extensively explores the concept of DA and approaches to death acceptance. It is understood that mindfulness and compassion might lead to acceptance. Evidence suggests mindfulness without compassion may provide some objectivity to what is being experienced, but no ability to soothe the self and reduce the potential for suffering afforded by compassion (Gilbert and Choden 2013) which is key to accepting death.

Regarding testability, the ideas/concept are supported by empirical evidence and contributes to the knowledge area. This paper expanded established knowledge on factors contributing to the development of DA and death acceptance from a Buddhist perspective. The next paper explored the process of DA through the experiences of terminally ill Buddhist patients.

Upasen et al. (2022) interviewed thirteen participants with advanced cancer about their experience of reaching acceptance with dying, with the findings suggesting a three-stage process (Appendix D). A grounded theory approach was used, whereby the researchers entered the study without preconceived ideas and uncovered core concepts by collecting, analysing and coding the data (Noble and Mitchell, 2016). The methodological approach appeared appropriate in answering the research question, as the researchers wanted to generate a theory around death acceptance for Buddhist cancer patients, which is different from an interpretive phenomenological approach which looks to understand the lived experience (Starks and Brown Trinidad, 2007). Considering the overall trustworthiness regarding credibility, Upasen et al. (2022) did consider the potential for bias by acknowledging prior experience within palliative care and their affiliation with Buddhism, they declared they had observed experiences of death acceptance in palliative care and attempted objectivity. It could be suggested that the researchers considered the findings' trustworthiness and dependability through peer debriefing within the research team and confirming the data with others who may share participants' experiences. That this reasoning contributed to including detailed accounts of data collection, including participant recruitment, specifics regarding the interview and data analysis process, coding, and thematic analysis. A purposive sampling

was utilised; however, to ensure all potential participants presented with a high level of death acceptance, they were asked to complete a death acceptance scale. The author suggests critical case sampling (Etikan et al, 2016) was also utilised as participants were chosen for their level of acceptance and strengthened to a level of dependability.

Regarding the transferability of the findings, this was considered low when thinking about local palliative patients because the participants were from Thailand and practicing Buddhists. The findings did have relevance when reflecting on the study participants' process of death acceptance (table three), discussion around death education and Buddhist contemplative practices appeared key to the process, and reflected what was experienced on the LWTDW course. Also, there was value in understanding the process and how taking part in the new MBI with a mixture of education and contemplative practice may assist participants to complete the three stages to death acceptance identified in the research. The next paper explores the impact of patient specific death education.

Kim et al. (2016) used a quasi-experimental approach to evaluate the impact of a death education programme for Korean breast cancer patients. Forty-eight participants were randomly allocated to an experimental (n=twenty-three) and a control group (n=twenty-five). There was no other comparable study, highlighting a gap in the research. Methodologically, specific enquiries are not conducive to laboratory conditions, and random allocation could not be achieved, which is why a quasi-experimental approach may have been used (Collins,

2007). It could be argued the researchers cannot create the same level of control over the participants and the environment outside laboratory conditions, so they cannot guarantee with certainty the intervention caused the effect (Parahoo, 2006). However, using a waitlist control group may be a helpful comparison as the author argues they have not yet completed the intervention allowing comparison. A comparison of the experimental characteristics with the control group noted an imbalance with two fewer participants in the experimental group. Participant numbers were small, leading to un-generalisable results for a broader population, weakening the validity of the study findings.

Methodological quality of this paper was considered, the researchers performed a power calculation before undertaking the study to gain an appropriate number of participants to strengthen validity and reliability of the findings (Crombie, 1996). It could be argued reliability was also strengthened by testing the instruments used to evaluate the intervention effect with the inclusion of the Cronbach Alpha test (Collins, 2007). The findings did suggest a reduction in fear of death following the intervention and increased fear of death in the control group, which suggests death education is considered beneficial to the participants. Regarding generalisability, the study participants were not representative of a local palliative population due to the small study population who were Korean and in remission from cancer. This paper was of interest in that the death education intervention was patient-specific, and certain aspects of the curriculum did overlap with that of the LWTDW course. Death education appears beneficial, attention was directed to exploring the impact of Buddhist meditation practices that focus on death in the next paper for discussion.

Stock (2018) explored death and dying in the context of Buddhism and ‘mindfulness of death’, also known as Maranasati. Through contemplation of death, stepping into discomfort leads to liberation and thriving with an appreciation of life. As with Michaud (2020), this paper is a discursive essay exploring this death meditation and its place in approaching death awareness from religious and theoretical perspectives supported by empiricism. Although the paper explores Buddhist death meditation with reference to theological and empirical viewpoints, as compared with Michaud (Ibid) there is no evaluation of the quality of the empirical studies and theories included. This paper had value as it introduced the concept of ‘mindfulness of death’ with reference to palliative care and how aspects of the practice could be integrated into clinical environments. Yet, it could be suggested it was written for clinicians, with Stock (2018) envisioning a spiritual retreat focused on death for palliative care professionals. Nonetheless, the subject matter and concepts introduced were transferable to palliative patients, such as introducing death meditations adapted and taught in retreat conditions. Exploring the limitations, having gained an understanding of ‘mindfulness of death’, it could be argued this practice with its eight approaches presented by Stock (Ibid) may be too radical for a western population where the concept of death is avoided. Alternatively, an adaptation that is culturally sensitive to local palliative populations is warranted. The next paper is a continuation into death meditation and its impact on DA and wellbeing.

Park et al. (2016) utilised a quasi-experimental approach to measuring the effect of Insight-Based Death Meditation on DA and quality of life through pretest-posttest measurement so cause and effect of the intervention were measured. Although the study findings claimed that the meditation programme lowered DA

and raised quality of life, arguably the results required scrutinising. Confounding factors were considered, variables unaccounted for that may have influenced the findings (Price et al, 2015). It was unclear whether the programme instructor was part of the research team, if this was correct, the participants' compliance may have been unduly influenced by the presence of the instructor who was guiding them through the programme and influenced the results. The researchers adapted recognised assessment scales for the Korean participants and considered internal consistency by checking the interpreted measurement tool. They demonstrated consistency with the recognised tool using Cronbach Alpha Tests, a marker of reliability in research (Collins, 2007). Considering the study's limitations, Park et al. (ibid) suggested that recruited participants were interested in meditation, which may have influenced the study's findings. The author questions whether the same results would have occurred with inexperienced meditators considering the intensity of the practice (forty-eight hours over six days). Also, the research does not provide details regarding the participant's meditation experience; it could be argued that being experienced meditators, participants were primed for a positive outcome. Regarding its broader implication for the new MBI for palliative patients, the findings are limited as the study participants were healthy Korean experienced meditators, enrolled in a programme that requires participants to commit an extended time of practice.

Analayo et al. (2022) explored the effect on death and DA by RCT; eighty-nine participants were randomly allocated to mindfulness (n=forty-four) and contemplation (n=forty-five) groups. Findings (table 3) suggested that both interventions reduce death and dying anxiety. Considering the research validity, block randomisation

was used to allocate participants into intervention groups. Kang et al. (2008) assert that this randomisation method involves randomly allocating participants to create a balance between the groups, which Suresh (2011) suggests is appropriate for small-scale trials of participant numbers below one hundred. There is a risk of selection bias as participant allocation could result in distinct contrasting groups (Kang et al, 2008). Referring to the demographic data, the author suggests an imbalance in the category of practicing for less than a year and practicing for more than one year in the mindfulness group, which could have influenced the results. In a traditional RCT, single and double blinding, where participants, investigators and data analysts are unaware of group allocation, may reduce bias (Parahoo, 2006). It could be argued that the lack of blinding reduced the study's methodological quality. However, in this type of trial where the intervention is not concealable such as in a drug trial, it could be argued it is impossible to conceal the allocation. The researchers provided both participant groups with the same protocols in that mindfulness and contemplation groups were given guided practices of the same length and instructed to practice for six weeks. However, they suggested confounding factors that could influence the findings; two different instructors were used to create mindfulness practices and one specialised in contemplative practices. The author suggests validity and reliability are strengthened by assessing the statistical significance and how probable the result happened because of chance (Carly and Lecky, 2003). Carly and Lecky (Ibid) do suggest that probability values of less than 0.05 indicate a high level of uncertainty and that a value of less than 0.001 denotes a stronger indication of the results not arising because of chance, which is what the researchers demonstrated in their findings (table three). The study population,

arguably, is not representative of a palliative population. Nonetheless, the findings had value, as the practices included in the trial's mindfulness intervention arm introduced the concept of impermanence considered relevant to palliative patients. The next theme considered studies that evaluate other mindfulness and compassion practices that could be included in the new MBI.

3.4 Mindfulness and Compassion Practices that Could manage DA in Palliative Care

So far, the review has provided insight into the roles of spirituality and mindfulness in palliative care and how Buddhism and approaches originating from this philosophy could help manage DA. The papers in this last theme evaluate mindfulness practices used with palliative patients.

The first two papers studied the effects of mindful breathing on suffering in palliative patients. Ng et al. (2016) performed a five-minute intervention and then later studied the effects of twenty minutes of mindful breathing (Beng et al, 2019). The findings of both studies indicated that mindful breathing does reduce distress in palliative patients (Appendix E). Methodologically, it could be suggested robustness was strengthened in the trial of twenty minutes of mindful breathing (Beng et al, *ibid*) demonstrated in the account of the research methods and presentation of data. Both trials considered the physical and psychological effects of mindful breathing; (table 4). Evidence suggests that by including both parameters, the objective physical measurement could be offset against the subjective experience, which may strengthen the validity of the findings (Van Dam et al., 2018).

Comparing the exclusion criteria of both trials, in the five-minute trial, people with respiratory/breathing difficulties were excluded; but were included in the twenty-minute trial. It could be suggested due to the statistically significant reduction in respiratory rate and distress levels in the five-minute intervention, the researchers took the decision to include participants who were dyspneic in the twenty-minute trial. The report of the five-minute trial presented the demographics in a paragraph, and the author suggests that by doing so, there was no clarity of how the characteristics of each group may have influenced the results, weakening the validity of the findings. A limitation of both trials was a lack of follow-up, the inclusion of long-term effects could have assisted in strengthening the evidence in support of the mindful breathing intervention. The author suggests taking the five-minute trial in isolation, the methodological rigour was weaker, in comparison to the twenty-minute intervention. It could be suggested the robust methodology of the twenty-minute trial strengthens the support for this intervention. Amongst the physiological effects of anxiety, is increased respiratory rate and state of arousal (Saric and McLeod, 2000). The findings of both studies suggest mindful breathing (Appendix E) promotes a state of relaxation and is considered a desirable practice for palliative patients. Conversely, breathing difficulties experienced by potential participants were acknowledged and required further consideration. The next study may provide insight into a practice that can cater for this group.

Lai et al. (2010) used mixed-methods research to evaluate guided imagery with theta music for dyspnoeic participants with advanced cancer. Evidence suggests the researchers provided an extensive rationale with a detailed explanation of how dyspnoea affects cancer patients physically and psychologically which supports the

need for a mixed-methods approach, as objective and subjective measurements may support each other; strengthening the findings' validity (Fetters et al, 2013). Arguably, that study's rigour was strengthened by inclusion of evidence-based measurement tools, pre-test-post-test measurement to reduce the risk of a false claim of therapeutic benefit and a detailed study protocol. Inclusion of non-participant demographics would have been appreciated in table form to be able to judge whether there were differences between the two groups instead of relying on the researchers' account. Fifty-six is considered a small sample population, so the sixteen participants who declined is a big enough number to affect the outcome of the study, if they had perceived the intervention as beneficial. Although the study findings (table four) suggest the intervention did benefit patients, they are limited due to a lack of a control group comparison, as there is no way of judging whether the effect would have occurred anyway (Parahoo, 2006). The study was a pilot; it could be argued that the researchers performed the preliminary investigation to assess the intervention feasibility and their intention behind the research. The guided imagery aspect of the intervention was of interest as the LWTDW course included guided imagery practices. The researchers did not evaluate theta music and guided imagery separately, so there is no way of judging the effect of guided imagery on participants in isolation. The study did report participants experienced no harm because of the intervention, which was viewed as promising. The study findings were inconclusive as to whether guided imagery in isolation is of benefit to patients who are dyspnoeic; nonetheless, given that no apparent harm came to the participants, guided imagery had promise. The next study was also a pilot that evaluated a guided imagery intervention which may assist in ascertaining benefit.

Sloman (2002) randomised fifty-six participants with a progressive malignant disease into one of four intervention groups. Comparing the previous study by Lai et al. (2010), this study evaluated guided imagery separately from progressive muscle relaxation and the combination of the two interventions, which assisted in distinguishing the treatment effects in isolation. Methodologically, a power calculation determined how many participants was needed to answer the research question, which is considered an indication of robust methodology, Sloman (2002) declared that a more significant participant sample was needed, which could suggest a level of transparency and strengthens the reliability of the findings.

It could be argued pilot research does not provide a definitive conclusion of treatment effect. Hassan et al. (2006) suggest that preliminary research helps identify difficulties and weaknesses before undertaking a complete study, Sloman (2002) stated their intention in undertaking the research was to identify patterns and trends. A search of Google Scholar showed no further comparative research for anxiety and depression and guided imagery by Sloman, which indicated no complete research was undertaken following the pilot. As argued by Freedland (2020), less than ten per cent of pilot studies of a small sample size progress to a complete study, one reason being that the pilot answers the research question. Although the randomisation of participants was mentioned, Harris et al. (2006) asserts randomisation is not a pre- requisite for a Quasi-experimental trial as the intention is to gain insight into intervention cause and effect for those who need it. The author argues the researcher does consider this, but with no detail it was unclear whether the approach taken may reduce the risk of bias, weakening validity and reliability of the findings. Participant demographic data were reported in

narrative form; presentation in a table format would have been appreciated to judge whether participants were similar in each group. An overbalance in specific characteristics may influence the findings, but also ascertain whether the findings may be generalisable to local populations. The findings (table four) suggest that guided imagery was not statistically significant in reducing anxiety; this appeared accurate for all treatment controls. Sloman (Ibid) does explore the reasoning behind the findings, which included a small sample population and the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) being sophisticated enough to assess subtle and significant changes in anxiety. The study did include some form of follow-up, where the participants had an opportunity to address concerns; the discussion mentions that most participants found the relaxation techniques helped to promote relaxation, which suggests no harm came to the participants. The inclusion of problems encountered would have provided insight into potential difficulties that could be encountered if working with local palliative populations. This study suggests guided imagery may not effectively manage anxiety in palliative care, the next paper may assist in arriving at a firm conclusion.

Arthsanthia and Triamchaisri. (2016) undertook a quasi-experimental approach to evaluate imagery meditation with end stage renal diseased participants. Evaluating methodological quality, the researchers measured sustained effects of the intervention over three months, whereas previous studies explored a single performance which was considered valuable regarding sustained treatment effects. Conversely, there was no mention of any follow-up on study completion, which would have provided further insight into the long-term treatment effects. As is the case with studying terminally ill participants, follow-up may not have been possible with no assurance

that participants would still be alive at follow-up, a previously identified limitation of palliative care research (Mok et al, 2010). One notable difference between the experimental and control conditions was the imbalance in participant numbers; thirty-five were allocated to the experimental group and thirty-nine to the control group, which may lead to inflated results. The author also considers whether the researchers had omitted to report that participants had dropped out of the experimental group, which could have invalidated the findings as those who dropped out may differ from the study completers (Bell et al, 2013). Price and Jhangiani, (2015) suggests that dissimilarity in participant groups is a limitation of the quasi-experimental methodology, and researchers need to take steps to increase internal validity by limiting confounding factors. The research failed to mention whether participants were experienced meditators which may have had a bearing on the validity of findings. It could be suggested that the reliability was considered by performing Cronbach Alpha testing to measure treatment effect (Price and Jhangiani, 2015).

Considering all three guided imagery studies in isolation the rigour of each study is questionable, however, in combination the evidence is strengthened with two of the study findings reporting positive outcomes for the management of anxiety in palliative patients. All three studies reported no intervention ill effects on study participants, which was considered important.

The final paper included in this theme is by Lim et al. (2021) who evaluated five-minute mindfulness on-love on the initial suffering of sixty participants who were randomly allocated to experimental (mindfulness of love) and

control (supportive listening) groups. The findings indicate statistically meaningful benefits (table four). There was no comparable intervention study, indicating a gap in the research. Lim et al. (ibid) initially considered effect size by basing their sample of participants on a previous research study, which Banerjee et al. (2009) assert is one way of estimating this. The author acknowledges that the researchers demonstrated rigorous methodology by performing a power calculation to identify an appropriate number of participants to increase the likelihood of accurate results. The study findings (Appendix E) suggest a positive outcome for the mindfulness of love intervention. The author suggests if those who had declined to participate had participated in the research had reported a negative effect may have impacted the findings (Patel, et al, 2003). of declined patient demographics would have been appreciated to be able to judge whether participants differed from those included. The author suggests rigour was strengthened as internal validity was considered with statistical testing to reduce the risk of a false positive result. A limitation of the study was the lack of follow-up; without this, there is no evidence to support its long-term effect (Carlson et al, 2016). The researchers declared that participants were voluntary and suggested previous mindfulness experiences may have influenced the results. It could be suggested the findings are not generalisable to a broader palliative population due to a small study population of predominantly Chinese Buddhists. Although this study evaluated a five-minute intervention with no comparative research, this MBI is considered of value because the study report stated that no harmful effects were stated by the experimental group, which suggests the intervention is safe with a palliative population and will consider this type of practice for inclusion in the adapted MBI.

Chapter: 4 Results

4.1 The Characteristics of the Evidence

The characteristics of the included literature are presented below. There was a mix of literature; eighty-one per cent of the included papers was classed as empirical research, with one-third comprising of quantitative data. Quasi-experimental and randomised control trials were equally dominant regarding methodology type. The United States of America was the dominant country of origin for included literature, which accounted for five papers. Twenty-seven per cent of the included papers were from Asian countries. Only thirteen per cent of the literature originated from Europe, including an empirical study published in the UK. The date range of included literature was from 1998-2022. Forty-five per cent of the appraised papers were published within the last five years, with eighteen per cent published in 2016. The findings of each theme are presented below.

Characteristics of Selected Literature

Types of literature	Quantity of Characteristics
Quasi Experiential	4
Randomised Controlled Trial	4
Interpretive Phenomenological Approach	3
Cross-Sectional Study	2
Mixed-Methods	2
Qualitative Study	2
Grounded Theory	1

Narrative Literature Review	1
Thesis	1
Expert Opinion	1
Discussion	1
Country of Origin	
United States	5
Thailand	3
Malaysia	3
New Zealand	2
South Korea	2
Indonesia	1
Australia	1
Hong Kong	1
Taiwan	1
Italy	1
Italy	1
Ireland	1
United Kingdom	1
Date of Publication	
2022	3
2020	3
2019	2
2018	2
2016	4
2014	1
2010	1

2009	1
2008	1
2005	1
2002	1
1998	1

4.2 The Role of Spirituality in Palliative Care

The findings of the cross-sectional study by Hardy (1998) indicated that spirituality might act as a buffer for DA in palliative patients. Spirituality was considered vital to the receptivity of palliative care (Chaiviboontham et al. (2014). Spirituality was identified with finding meaning, purpose, and social connectedness (Rake-Marona, 2018; Nakashima et al., 2005; Yosep et al., 2022; Mok et al., 2010). Spirituality was associated with assisting in the process of letting go and moving into acceptance of life ending (Rake-Marona, 2018; Nakashima et al., 2005; Mok et al., 2010). Spirituality was also associated with having a faith (Moke et al., 2010; Rake-Marona, 2018; Yosef et al., 2022). Rake-Marona (2018) highlighted its role in living well while dying and how spirituality provides an opportunity to consider personal legacy and the contribution one has made to future generations. She also highlighted its function in promoting acceptance of the unknown. Nakashima et al. (2005) highlighted how spiritual practices and beliefs might assist in skillfully navigating death and how spirituality provides an opportunity for a life review through narrative leading to insight and acknowledging past achievements. Yosep et al. (2022) identified how spirituality engenders gratitude, equanimity and optimism.

4.2 Mindfulness-Based Interventions and palliative care

The findings of the thematic analysis undertaken by Zimmerman et al. (2020) identified a change in perspective after completing their MBI with transformation of fear and anxiety to feelings of tranquility, calm and acceptance. Quantitative findings of the mixed methods study by Polletti et al. (2019) on MBSR with palliative patients identified no statistically significant impact on pain reduction but a significant reduction in fatigue and depression. Qualitatively, participants reported changes in perspective, including increased interoception, opening to and processing the pain experience, and using inner resources to manage pain. The researchers identified that DA became apparent by the fourth week of the course, but the anxiety was managed through the practices introduced. They also identified a reconnection with spiritual values from undertaking the MBI, which was considered a supportive intervention by participants. Chadwick et al. (2008) also noted that participants reported associating their MBI with new ways of pain management, but also a positive change to illness perception. The MBI was considered consistent with the Christian faith by one participant. The intervention was group-based, which participants considered valuable and promoted group cohesion and social connection, which was an observation also noted in the findings by Polletti et al. (2019). Polletti et al (ibid) also noted study participants considered the hospice as being a supportive environment under which their MBI occurred. Also noted in their research was participants did not always undertake practices at home. The findings of the Interpretive Phenomenological approach undertaken by Shannon (2020) highlighted the effect of an MBI on participants after a year of practising mindfulness. As with Chadwick et al. (2008) and Polletti et al. (2019),

participants developed interoception and felt empowered to manage their pain. Participants reported increased emotion and thought regulation through the calming effect of mindfulness practices. In undertaking the MBI, participants were more likely to live in the present, with an altered perspective of living with a terminal illness.

4.3 Approaches to the cultivation of acceptance of death and dying

Michaud (2020) highlighted that death acceptance does not eradicate anxiety, however, tolerance can be cultivated through mindfulness, meditation and compassion. The study findings of Analayo et al. (2022) supported assertions made by Michaud (ibid) in that mindfulness practice might reduce fear of one's death, and that of others but increases fear of dying in others. Upasen et al. (2022) identified a three-step process of death acceptance in Chinese Buddhist cancer patients; inviting the suffering in, willingness to acknowledge the possibility of death and maintaining new beliefs with Buddhist practices; which included a combination of education and contemplative practice. The study's findings on a patient- specific death education programme undertaken by Kim et al. (2016) indicated that death education might reduce fear of death and increase spiritual well-being through discussing matters related to preparing for death. Stock (2018) explored Buddhist death meditation which suggested that by contemplating death, one accepts impermanence, thus reducing fear, leading to acceptance and reduction of suffering along with clarification of priorities in life. Study findings exploring the effects of Insight death meditation practiced consistently support the concepts presented by Stock (ibid) in that Insight death meditation may reduce DA.

4.4 Mindfulness and compassion practices that could manage DA in palliative care

Findings of the trial of five minutes of mindful breathing was considered beneficial in reducing distress physiologically and psychologically in palliative participants compared to standard listening (Ng et al., 2016). On the back of those findings, twenty minutes of mindful breathing was considered as effective at managing distress as supportive listening but more effective at managing pain (Beng et al., 2019). The findings of imagery meditation practices presented mixed findings. Guided imagery with theta music reduced physiological responses associated with stress response (Lai et al., 2010). In contrast, the findings of quasi-experimental research into guided imagery alone did not appear to have a statistically significant reduction in anxiety but a notable improvement in depression and quality of life (Sloman, 2002). However, the study findings of Artsanthia and Triamchaisri. (2016) indicated that sustained Imagery meditation practice might improve quality of life and reduce physical symptoms, including anxiety. The findings of a trial of five minutes of mindfulness of love had a statistically significant benefit on acute suffering and quality of life spiritually compared with supportive listening (Lim et al., 2020).

Chapter 5 Discussion

This review aimed to synthesise the literature on the key considerations when designing an MBI to manage DA. Critical concepts presented in the introduction highlighted the societal contribution to the taboo surrounding death, leading to anxiety, with medicine replacing the clergy in the role of death education. Dying well was associated with open conversations about death with others, meaning-making, and finding and taking in good experiences. Mindfulness is emerging in palliative care as a non-pharmacological approach to managing symptoms. A gap was identified in the literature around death education programmes for palliative care patients. This literature review sought to address this by creating a new MBI for palliative patients.

5.1 Statement of findings

The findings highlighted that anxiety around death and dying may always persist. Nonetheless, contemplative practices and formalised death education that focus on preparing for death may assist in promoting acceptance and resilience in dying. Spirituality has a role in navigating the dying process and helping patients to live well while dying. As a spiritual practice, mindfulness manages palliative illness non-pharmacologically by adjusting mindset to increase symptom tolerance and includes breathing, loving kindness and imagery practices.

The selected review of literature was a mix of empirical, discursive and theoretical papers. Arguably, this combination complemented each other, with the theoretical and discursive papers introducing concepts and perspectives and empirical studies providing evidence to support theoretical and experiential perspectives,

considered a strength of the Integrative Review. Trial research dominated, with quantitative studies overshadowing qualitative exploration. Lincoln and Tierney (2004) suggest ethics review boards contribute to the favorability of quantitative research, citing a lack of understanding of how qualitative data will contribute to a body of knowledge and how criteria for assessing studies for ethics approval is not always adaptable to qualitative studies, a perspective supported by Gysels et al. (2013). Gysels et al. (ibid) suggest mixed-methods research is preferable, which is also welcomed in mindfulness research (Van Dam et al., 2018). Studies by Lai et al. (2010) and (Polletti et al. (2019) were the only two studies that used mixed methods; reviewing the methodology presented by Polletti et al. (ibid), the research is predominantly qualitative. It could be argued that pain assessment, a quantitative measurement, was included to gain ethics board approval. Considering the paradigm of Interpretivism associated with this research, quantitative data was initially not considered relevant to the investigation, as knowledge of subjective experience (qualitative) was favoured over cause and effect (quantitative). Nonetheless, with reference to page sixteen, the research question for this review provided scope to include both kinds of findings, which resulted in a comprehensive assortment of papers, allowing flexibility in answering the research question (Tronto, 2020) and suited to IR as a review methodology.

The review findings supported the creation of the new MBI, with benefits including a mindset shift in how terminal illness is perceived and managed and led to consideration of how to adapt the LWTDW course. Considering the difference between education in the form of a course, which involves teaching subject matter (Collins 2023), and an intervention which is an act of treatment to improve a medical condition (National Cancer

Institute, 2023) which calls for specialised knowledge of the patient group. Crane et al. (2016) support this assertion suggesting that an MBI requires the teacher to have the training and experience specific to the population/setting. Referring to the discussion with the KI on page ten, consideration was given to living well while dying with a palliative illness; it could be argued that the LWTDW course is pitched towards the general population and not palliative patients who experience life complicated by symptoms. The new MBI will have a teaching element to the weekly sessions, where patients will be taught non-pharmacological approaches to managing common symptoms, which include dyspnoea, fatigue, pain, and anxiety (Henson et al, 2020). By doing so, patients may feel empowered to manage them independently, thus reducing contributory variables that may contribute to DA.

One clinician with palliative care expertise who is also a mindfulness teacher is considered ideal; however, palliative care encompasses multiple professionals who are specialists in their field. The challenge will likely be to find health professionals who are competent in teaching mindfulness with expertise in subjects such as dyspnoea and fatigue management. Alternatively, multidisciplinary team (MDT) members will teach management strategies to the patients as part of the intervention, with a mindfulness teacher leading the mindfulness practices. Multidisciplinary working is the ethos of palliative care, whereby specialists contribute their expertise toward patient care (Vissers et al, 2012). Consequently, mindfulness practices will need to be adapted to the patients' needs, including positioning and suggestions of techniques to assist them in performing

mindfulness practices comfortably, which would require consultation with the MDT. By involving the MDT, they may understand the role of mindfulness in palliative care and promote the dissemination of the new MBI.

Observations noted by Polletti et al. (2019) that DA appears to present at the midpoint of MBSR, it would appear appropriate to progress onto the LWTDW course on week four/five, which will structure the rest of the intervention. The LWTDW course included a weekend-long retreat with six bi-monthly check-ins where new themes and practices were introduced. Considering the MBI is adapted for palliative patients whose life expectancy could be less than a year, the intervention will include nine weekly sessions and several additional sessions that will occur monthly. The monthly sessions are considered important to help promote sustained motivation to keep up with mindfulness practices. Also, participants may find the support cultivated because of the group setting a comfort as they enter the later stage of the palliative illness. Consideration was also given to the session length, comparing course structure for the interventions identified in the review ranged from thirty minutes (Zimmerman et al., 2020) to sixty minutes (Chadwick et al., 2008) and one hundred and eighty minutes (Polletti et al., 2019). Referring to the discussion with the KI on page ten, they suggested one hundred and twenty minutes, including multiple breaks with practices of a shorter duration of twenty minutes. Personal experience of running the Mindfulness-Based Living Course (MBLC) (Appendix E) created by the MA (Choden and Regan-Addis, 2018), one hundred and eighty minutes is considered an appropriate length which will include breaks.

One hundred and eighty minutes would appear realistic, given that this intervention will include education and contemplative practices. Searching for empirical studies related to the MBLC, the MA performed pre-test and post-test analyses, which showed statistically significant effects on stress reduction (Mindfulness Association, 2017) comparing course content with the MBSR (Centre for Mindfulness Research and Practice, 2018) (Appendix F) which has been the focus of multiple studies (Kabat-Zinn, 2003; Baer and Carmody, 2012; Koury et al, 2015; Choobforoushzadeh et al, 2023) both courses cover similar content. Merging the MBLC with the LWTDW course would appear reasonable, as the MA created both courses.

Only one patient-specific death education course was identified, trialed by Kim et al. (2016); as mentioned on page twenty-eight, this was specific to individuals in remission from cancer. Comparing the LWET course introduced on page five created by Slater et al. (2018), both courses had different approaches; the LWET course was religion specific, and the Dying Well education programme was clinically focused. The commonality identified in both studies was an appreciation of open dialogue around death. The curriculum included in the Dying Well education programme (Kim et al., 2016); overlapped with the LWTDW course, which included the dying process, writing a will and a life review. It also included content on a good death; it could be suggested that caution is warranted when defining a good death, as every experience will be unique. McNamara (2004) argues for a change in expectations to one of a good enough death as palliative care professionals navigate patient care with all its complexities. It could be argued that establishing what a good death may look like, could mislead patients and trigger DA and will not be included in the new palliative-specific MBI.

The phase of illness was considered regarding potential participants; referring to the discussion with the KI on page 10, they suggested anxiety occurs around the fear of experiencing palliative symptoms. Alternatively, Chin et al. (2022) suggest anxiety exacerbates presenting symptoms associated with palliative illness. On reflection, the KI does make a good case for approaching the perspective of symptom management, which may relieve anxiety. However, this intervention intends to manage DA, as it could be argued that fear of death underlies how a palliative illness is experienced. As with anxiety, palliative symptoms in whatever form they take will likely present, and it is about developing acceptance toward those symptoms through utilising mindfulness practices. Therefore, patients considered at an early stage with a Karnofsky performance status of between one hundred and eighty per cent, whereby confirmation of a palliative diagnosis has occurred, and symptom burden is not impeding daily life (Oken 1982, cited in European Society of Medical oncology, 2023) will be invited to participate. It could be argued that at this stage, their initial concern is that they will die. Palliative symptomology will not have been anticipated at the initial stage of prognosis. It could be argued the development of a sustained mindfulness practice, which promotes acceptance of death, will reduce symptom burden and will be explored next.

Arguably, it is likely that participants will be inexperienced in mindfulness, which was a consideration by Shannon (2020) in his research. Delving straight into the LWTDW course curriculum may only be fully appreciated with understanding and embodying the foundations of mindfulness, which include settling the mind, grounding in the body and resting in awareness (Choden and Regan-Addis 2018). A systematic review of papers

on neuroimaging identified functional changes in the Insula and anterior cingulate cortex following completion of a MBI, which are involved in developing internal awareness and processing emotional and environmental cues, emotion regulation, and cognitive distancing (Young et al, 2018). By strengthening these brain areas through the foundations of mindfulness practice, participants may develop enough resilience to consider the idea of dying. Alternatively, Britton (2019) argues that activation of the insula cortex can trigger anxiety, which could be an issue as the new MBI intends to manage death anxiety. On reflection, a combination of compassion and mindfulness may assist in promoting self-soothing and reducing anxiety levels. Compassion has been associated with high vagal tone and activation of the parasympathetic nervous system resulting in feeling safe (Wong, 2021). Given the above evidence, including a compassion practice would be vital early in the intervention.

Referring to page forty-one, only one of the selected review papers explored the impact of loving-kindness practice on palliative patients (Lim et al., 2021). Although considered necessary when considering DA, there is awareness of the potential reactions to introducing compassion, especially with individuals with low self-compassion. As compassion develops in the self, participants who may not have experienced much in the way of previous healthy nurturance and may experience the surfacing of old patterns and beliefs that counter the emergence of compassion that Germer (2019) calls backdraft. In this instance, the role of the mindfulness teacher is to hold the space creating a safe environment for the person experiencing this to process it, as it is

considered evidence of healing (Germer, *ibid*). The mindfulness teacher's effective use of inquiry skills will help facilitate the process and is a critical aspect of any MBI (Crane et al., 2016).

Consequently, participants must be offered support within and between sessions to discuss any experiences that may arise from the MBI. If the intervention triggers participant distress beyond the capabilities of the mindfulness teacher, they will be referred for psychological support. Participants will also be reassured that if they wish to discontinue the intervention, they can do so and follow-up will be provided in the form of aftercare.

Of the few practices that were the focus of studies identified in the literature, breathing practices were considered beneficial (NG et al., 2016; Beng et al., 2019). However, not all patients may find focusing on the breath straightforward. Ambrosino and Fracchia (2019) assert that persistent dyspnoea is associated with Chronic Obstructive Airway Disease and lung cancer, which can occur despite medical intervention. The act of breathing involves a combination of physiological mechanisms, including receptors in the lungs and respiratory muscles, and neurological mechanisms through vagal, phrenic and intercostal nerves. The central nervous system is the hub where the neurophysiological information is synthesised and coalesced (Ambrosino and Fracchia, (2019). It is understood that nervous system dysregulation and the activation of brain regions such as the insula cortex are associated with an anxiety response (Britton, 2019). On reflection, a predisposition to a dysregulated nervous system may likely trigger anxiety, and dyspnoea may further exacerbate the anxiety response. Traditionally, the MBLC practices include breath support as one of the anchors to bring awareness to

the present moment (Choden et al., 2018). Focused awareness meditation involves sustained, focused attention on an object (Lutz et al,2008); in this case, alternative anchors will be offered such as a candle, sound, or aroma which may assist in directing the attention away from the breath. On reflection considering the teaching element of the intervention, dyspnoea management may provide techniques that can be used to adapt the practices, such as the calming hand technique, body positioning and use of a hand-held fan (Ambrosino and Fracchia, 2019; Swan et al, 2019; Lockett et al, 2022) that may assist the patient in comfortably practising mindfulness practices.

The review findings indicated that Buddhist death meditation referred to on pages thirty-one through to thirty-three could assist in managing DA. Referring to the literature on preparing for death from the Buddhist perspective, death is accepted as inevitable and is perceived as an opportunity; contemplating one's death is actively encouraged as it is a chance to consider what is essential in life (Khyentse, 2020). In the book entitled *Living is Dying: How to Prepare for Death, Dying and Beyond* (Jamyang, 2020), several mindfulness practices were suggested, including instruction on contemplating death before sleeping and reminding oneself of the stages of dying, which relates to preparing for the dissolution of the body. They invited one to imagine the body deteriorating as it would when actively dying. Reading both practices as a Westerner triggered a fear response, which may be intensified if faced with a terminal diagnosis. The LWTDW course did discuss the stages of death compassionately and introduced the concept of dying. This took the form of a reflective practice where the course participants are invited to reflect on the question, *if I had six months to live, what would I nourish and*

what would I let go of taken from the publication 'A Year to Live' (Levine, 1998). Levine dedicated his life to teaching Theravada Buddhism with specific interests in providing support for people at the end of life (Levine S and Levine, 2023; Wikipedia, 2022). It could be suggested Levine acknowledged the Western propensity for DA and introduced the notion of impermanence indirectly. This practice is considered an appropriate alternative to the Buddhist death meditation and will be included in the new MBI.

The rigour of the studies included on imagery practices could be considered weak, leading to questioning the validity of study findings; nonetheless, as stated in the appraisal, there was no indication that imagery practices harm. Conversely, according to Britton et al. (2021) meditation related side effects/adverse events are not always communicated, citing less than twenty per cent of meditation reporting an adverse event, which included failure to recognise side effects, a reliance on research participant report, and downplaying side effects in the interests of research funding. It may be in the researchers' best interests to omit any mention of harm to get their research published (Suri, 2020). On reflection, awareness of the likelihood of non-reporting of adverse events was acknowledged, considering the types of imagery practices included in the LWTDW course, such as 'taking in the good' and 'compassionate being and safe place' These imagery practices are compassion-based and are designed to activate the parasympathetic nervous system which is associated with feeling safe (Gilbert et al., 2013) thus reducing the of risk of harm. Given the evidence, imagery practice is considered appropriate and will be included in the MBI.

5.2 Presentation of New MBI for Palliative Care Patients

All literature was appraised, and considered in conjunction with input from the KI which has resulted in the creation of the new MBI which is presented in its basic form below.

Living Abundantly While Dying; New MBI for Palliative Patients for managing DA

Week	Introduction/ homework review of home practice	10 minute break	Teaching/discussion Topics 20 minutes	10 minute break	Practice and Inquiry 25 minutes	10 minute break	Practice and Inquiry 20 minutes	Homework and questions
1	Introduction of group members. Talk about the course		What is Mindfulness?		Raisin/chocolate practice		Recognising the unsettled mind and Settling the mind	Discussion on support, and homework, give out workbook.
2			Pain management		Compassionate Body Scan		Memories of kindness	
3			Fatigue management		Mindful movement/walking		Three stage breathing space	
4			Breathlessness management		Settling, grounding and resting with the support of breath, sound, sight, aroma		Loving Kindness for self	
5			Anxiety management		RAIN practice		Self-Compassion Break	
6			Introducing the stages of dying		If I had a year to live reflection		Taking in the Good practice	
7			Experiences of death		In the end reflection		Safe Place and Compassionate Being	
8			Advanced Care planning		Living without regret reflection		Tonglen for self	

9			Wills and power of attorney		Tonglen for other		Mindful movement/sitting	
10			Resentment		Resentment reflection		Revisit Self compassion break	
11			Funeral Planning		If I had six months to live reflection		Body like a Mountain Compassionate Breathing	
12			Moving forward after the course		Reflection on one thing that will be taken with and one thing that will be left behind		Closing ceremony and goodbyes	

5.3 Limitations

This review highlighted a dearth of literature that originated in the UK; only one of the included studies was British (Chadwick et al., 2008) which limited the generalisability/ transferability of the findings to local palliative populations. Evidence suggests ethical issues in undertaking research in palliative care may be a contributory factor as to why more research is not performed in the UK (Gysels et al., 2012; Gysels et al., 2013; Abernethy et al., 2014). A fundamental belief is that palliative patients are too vulnerable to participate in the research process; (Gysels et al., 2013; Emmanuel et al., 2004). An integrative review undertaken by Gysels et al. (2013) into perspectives and experiences of research participation challenges this notion. It suggests that patients would be open to the idea of research participation. A UK workshop focusing on appropriate standards for research ethics identified paternalistic beliefs held by gatekeepers and ethics review boards, contributing to limited access to potential palliative participants (Gysels et al, 2013; Fine, 2003). The Cross-Sectional Study

included in this review undertaken by Hardy (1998) on page seventeen supports this perspective suggesting that the fear of gatekeepers, healthcare professionals taking care of the participants, may have influenced the responses and potential of other patients not participating in the research. Also that palliative patients may initially find discussing death and dying stressful but see benefit from talking about such issues, which does suggest the onus could be placed on patients as to whether they wish to participate, which was also included in the findings of a prospective cohort study performed by Emmanuel et al. (2004) exploring discussions of death, dying and bereavement with terminally ill patients and carers. Referring to the date range of literature appraised (table five), more studies are happening with palliative patients, which may indicate that culture is changing with a benefit of studying this patient group realised and how their insights may help to develop practice.

Another limitation of the review was that the author performed the research independently. According to Tronto (2020), an IR is performed by two or three reviewers, which would allow the team to perform an exhaustive search of the literature, which may involve a broader scope for literature searching, such as non-English papers and grey literature, which did not occur in this review. Analysis of the data highlighted a preference for qualitative studies over quantitative research, with confidence observed in appraising qualitative studies, which may be reflected in the quality of analysis of quantitative data. Multiple reviewers may have led to a more robust analysis of selected papers, as a consensus of agreement may have been reached as to the studies, which may be reflected in the quality of analysis of aspects of the papers' methodology that may have

influenced the review's findings (Remington, 2020), is acknowledged. All literature appraised in some form will have some form of bias, and finding studies without some error is considered unrealistic.

This IR only identified three types of meditation practices that had been trialled with palliative patients; the recommendation for future research would be to perform more robust research of breathing, loving kindness and guided imagery with palliative patients to increase the evidence base given the small number of trials. No trial research was identified on the benefits of guided reflection, where a question becomes the focus of the practice and space is provided to allow response in the form of thought and feelings that may provide insight (Choden and Regan-Addis, 2018). Also, Tonglen is a compassion-based meditation practice that asks the practitioner to take in suffering through the breath and send out loving kindness with the out-breath for the benefit of others (Gilbert & Choden, 2013). The recommendation for further research would be to trial both practices with palliative care patients to ascertain their effectiveness.

5.4 Dissemination

The author has discussed with members of the MA who have expressed an interest in making this MBI a reality whereby the intervention will be trialled with a group of palliative participants in the author's workplace. If successful, it could be made accessible to more palliative populations nationwide through formalised training. Consideration of the potential to publish this research detailing the intervention to promote interest in this potentially valuable palliative care approach is also possible. The experience, and the knowledge developed from

undertaking the project, has enhanced professional development regarding a new appreciation of evidence-based practice, palliative patients' concerns around death and dying, and skills/techniques that can be incorporated into patient care.

6 Conclusion

The Integrative review sought to appraise the literature regarding the management of DA in palliative care patients, resulting in creating an MBI adapted with symptom management in mind. The MBI created is unique in palliative care in that it is spiritually focused and encompasses symptom management strategies instead of symptom management being the dominant focus. The review's findings indicated spirituality has its place in navigating end-of-life through meaning-making, promoting acceptance and shared humanity. A combination of education on symptom management, mindfulness and compassion, were considered beneficial in promoting a shift in perspective dying. Along with approaches to coping with a terminal illness introduced at an early phase. Although anxiety and common palliative symptomatology may persist, mindfulness, compassion and practices associated with the wisdom tradition of Buddhism may assist in promoting acceptance and reducing suffering.

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Appendix A

University Ethics Form

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School of Education
MEd/MSc Masters Project/Dissertation

Full Proposal/Ethics Form Feedback

Student name: Linssay Lister
Supervisor: Prof Graeme Haan
Second marker: Colette Savage
Date:

	Satisfactory preparation made	Area for further discussion as you continue with your project	Revisions required before full proposal can be accepted	Not addressed or missing
Professional title	✓			
A rationale for your research, demonstrating reflection on your professional practice, engagement with others and a clear understanding of the wider context within which you operate. An explanation of why your project is important or necessary and identification of the key areas of concern.	✓			
A literature review, demonstrating critical	✓			

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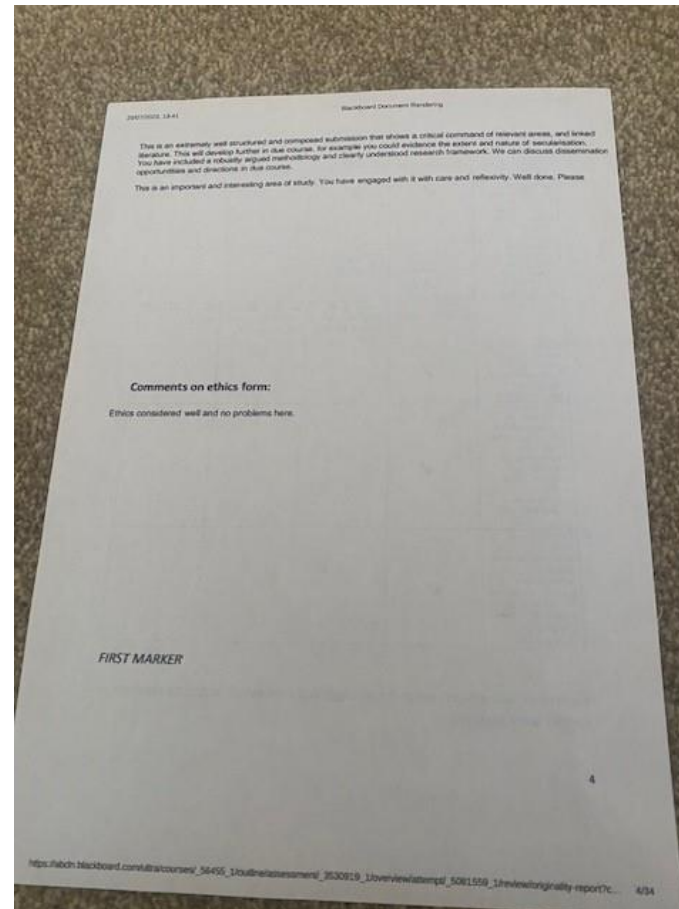
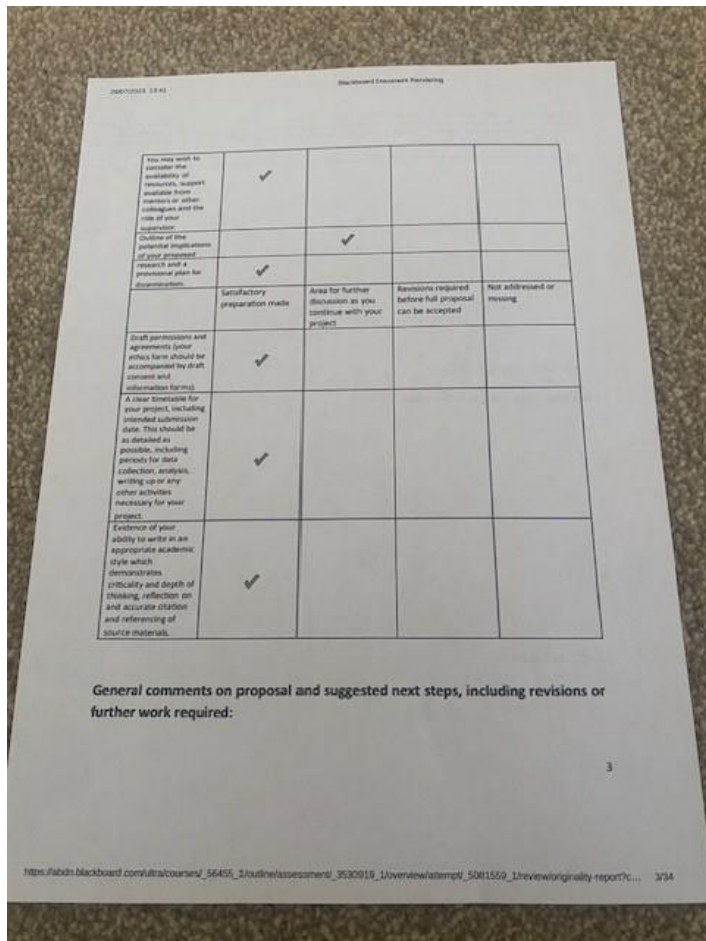
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engagement with appropriate sources, an understanding of relevant theoretical or conceptual issues, and an appreciation of current research and discourse in your domain of interest.	✓			
A clearly articulated research question or development goal and associated objectives.	✓			
Justification for the research or development approach, indicating awareness of research frameworks.	✓			
A detailed consideration of methodological issues including data collection methods and proposed data analysis, or for a development project, full details of your intended intervention and evaluation approach. Draft research instruments should be included as appendices. You should make it clear how your intended research will address your research question or development goal.	✓			
Discussion of ethical or any other sensitive issues including privacy, confidentiality, and avoidance of harm to participants and yourself. Particular attention should be paid to these issues where projects involve working with children or vulnerable adults.	✓			
Assessment of risks and support issues.	✓			

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Appendix B

Table one: Literature exploring the role of spirituality in palliative care

Number	Author and Year	Title of Paper	Type of Literature	Country	Main Summary of the Findings
1	Hardy (1998)	The impact of spirituality on Death and Dying Anxiety among Hospice Patients	Cross-sectional study	United States of America	Spirituality appears to be negatively correlated with death and dying anxiety in hospice care patients. A presence of meaning and purpose helps to overcome death anxiety into a mindset of acceptance of the dying.
2	Chaiviboontham (2014)	Factors predicting the effectiveness of palliative care in patients with advanced cancer	Cross-sectional study	Thailand	Statistical analysis indicated spiritual wellbeing was found to be significant in the effectiveness of palliative care with narrow confidence intervals (1.031-1.083) and probability values of 0.000
3	Yosep et al, (2022)	Spiritual Needs in Cancer Patients: Narrative Review	Literature Review	Indonesia	Spirituality is associated with the following themes; (1) provides meaning and purpose, (2) provides fortitude in faith, (3) cultivation of thankfulness, equanimity, and optimism and (4) social support.
4	Rake-Marona, (2018)	Creative Surrender:How we grow at the end	Expert Opinion	United States of America	The potential for spiritual growth at the end of life, common themes included finding meaning and purpose, letting go and finding authenticity, death is an invitation to live well

					while dying, the importance of social connection and having faith in the unknown.
5	Nakashima et al (2005)	Positive dying and resiliency in later life: A qualitative study	Qualitative Study	United States of America	Constituents of spirituality associated with hardiness included strong relational bonds, spiritual beliefs and rituals, adeptness in facing death, care environment that promotes safety.
6	Mok et al. (2009).	The meaning of spirituality among the Hong Kong Chinese Terminally Ill	Interpretive Phenomenological Approach	Hong Kong	Four key themes and seven sub-themes were identified, which included; life is a combination of mind, body and spirit; death acceptance is associated with surrender, equanimity and peace; finding meaning and purpose in life; the importance of social connections.

Table two: Literature exploring mindfulness-based interventions and palliative care

<u>Number</u>	<u>Author and Date</u>	<u>Title of Paper</u>	<u>Type of Literature</u>	<u>Country</u>	<u>Main Summary of the Findings</u>
1	Zimmermann et al (2020)	Patients' experiences of a mindfulness intervention for adults with advanced cancer: a qualitative analysis	Qualitative exploration, including Thematic Analysis	New Zealand	The findings of Coping with Cancer Mindfully an MBI for adults with advanced cancer. identified multiple themes pre- and post-intervention around changes in perspective from fear and anxiety before to feeling peace, calm and acceptance post-intervention.
2	Shannon (2020)	"Eternity in an hour...." Exploring the role of mindfulness with patients receiving Palliative Care- an Interpretive Phenomenological study.	Qualitative study, Interpretive Phenomenological Approach	Ireland	Several themes were identified, including new ways to approach pain, emotional regulation, and a change in perspective regarding how a terminal illness is viewed.
3	Poletti et al. (2019)	Mindfulness-Based Stress Reduction (MBSR) in early palliative care for people with metastatic cancer: A mixed methods study.	Mixed-Methods	Italy	MBSR with palliative participants was statistically significant in improving depression (.00) and fatigue (.00). Three main themes were identified from qualitative analysis, included increased body awareness, changes in

					approaches to cancer-related pain, inner pain resourcefulness and benefits of a supportive environment.
4	Chadwick et al. (2008)	Mindfulness groups in palliative care: a pilot qualitative study	Qualitative study Interpretive Phenomenological Approach	United Kingdom	Seven themes associated with participating in an MBI included social connection, improving quality of life and relating to illness differently.

Appendix D

Table Three: Literature Exploring Approaches to the Cultivation of Acceptance of Death and Dying

Number	Author and Year	Title of Paper	Type of Literature	Country	Summary of Findings
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1	Michaud (2020)	Attitudes Towards Death: How Buddhist Teachings Help Cope with Death Anxiety and Accept Death	Thesis	United States of America	Death anxiety is complicated, by background, age and culture. Acceptance of death does not eradicate anxiety, but, through approaches such as meditation, mindfulness, and compassion, cultivation of tolerance, which includes emotional regulation and present moment awareness can assist in an appreciation of the life being lived.
2	Upasen et al. (2022)	Death Acceptance Process in Thai Buddhist Patients with Life-Limiting Cancer: A Grounded Theory	Qualitative-Grounded Theory Approach	Thailand	The findings from interviews with thirteen patients with terminal cancer identified three main themes in the process of acceptance; (1) inviting the suffering in, (2) willingness to acknowledge the possibility of death and (3) maintain the establishment of new believes with Buddhist practices.
3	Kim et al. (2016)	The effects of Dying Well Education Program on Korean women with breast cancer	Quasi-Experimental Study	Korea	The findings suggested participants who completed the course did experience reduced fear of death, increased spiritual wellbeing and found benefit in discussions around subjects associated with preparing for death.
4	Stock (2018)	The Art of Dying as the Art of Living: Exploring Buddhist Death Meditation as a Path to Human Flourishing	Discussion	United States of America	Spirituality in this instance, Buddhism can inform the concept of death. Through contemplating death, impermanence may be accepted leading to living an authentic life and the potential to thrive. How aspects of the 'mindfulness of death' can

					be integrated into palliative care, such as, focusing on nonattachment and present moment awareness and the importance of talking about death to identify what matters in shared discussions in community.
5	Park et al (2016)	The Effect of Insight Based Death Meditation on Death anxiety and Quality of Life	Quasi-Experimental Research Study	South Korea	Insight Based Death Meditation was found to have a significant impact on reducing death anxiety and improving quality of life of Korean participants
6	Analayo et al. (2022)	Effects of Mindful Practices on Terror of Mortality: A Randomized Control Trial	Randomised Control Trial	New Zealand	Mindfulness practice was as effective as contemplative practice at reducing fear of death of the self and others but increases fear of dying in others.

Appendix E

Table four: Literature Exploring Mindfulness and Compassion Practices

Number	Author and Date	Title	Type of Literature	Country	Summary of Findings
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1	Beng et al. (2019)	The Effect of 20-Minute Mindful Breathing on the Perception of Suffering and Changes in Bispectral Index Score in Palliative Care Patients: A Randomized Control Trial,	Randomised Control Trial	Malaysia	Both twenty minutes of mindful breathing and supportive listening were considered effective at managing distress, the benefits were seen earlier in mindful breathing than the supportive listening for suffering. Pain reduction was statistically significant in mindful breathing compared with supportive listening and the Bispectral Index Scores indicated consistency in all time frames with Mindful Breathing compared with supportive listening.
2	Ng et al. (2016)	The effect of 5 minutes of Mindful Breathing to the Perception of Distress and Physiological Responses in Palliative Care Cancer Patients: A Randomized Controlled Trial Study.	Randomised Control Trial	Malaysia	Five minutes of mindful breathing was found to be statistically significant in reducing distress using mindful breathing in comparison to standard listening control, in the effects psychologically and physiologically.
3	Lai et al (2010)	Efficacy of Guided Imagery with Theta Music for Advanced Cancer Patients with Dyspnoea: A Pilot Study.	Mixed methods study	Taiwan	The findings suggest guided imagery with theta music resulted in a statistically significant reduction in respiratory rate, heart rate, subjective report of breathlessness and end tidal carbon dioxide, but no statistically significant response to increasing blood oxygenation.
4	Artsanthia et al (2016)	The Effect of Imagery Meditation Healing Exercise (SKT6) in Palliative Care for People Living with End Stage Renal Disease	Quasi Experimental Study	Thailand	Findings suggest after three months of practicing imagery meditation improves quality of life, a reduction in physical symptoms which included anxiety.
5	Sloman (2002)	Relaxation and Imagery for Anxiety and Depression Control in	Quasi-Experimental Study	Sydney, Australia	Findings suggest guided imagery had no statistically significant reduction in anxiety, but notable improvement in depression and quality of life.

		Community Patients with Advanced Cancer			
6	Lim et al (2020)	The effect of 5-min mindfulness of love on suffering and spiritual quality of life of palliative care patients: A randomized controlled trial study	Randomised Controlled Trial	Malaysia	Five minutes of mindfulness of love was found to have a positive impact statistically on acute suffering and quality of life spiritually compared with supportive listening.

Table 5: Mindfulness Based Living Course

Week	Title of Week	Practices and subject matter
1	Start Here and Now	Guided Reflection on Intention and Motivation, Recognising the Unsettled Mind and Settling the Mind practices
2	The Body is Always Here and Now	Body Scan, Mindfulness in Daily life, Introducing Kindness, Memories of Kindness Practice
3	Introducing Mindfulness Support	Introducing Settling, Grounding and Resting and Mindfulness Support of Sound, Three Stage Breathing Space practice.
4	Working with Distraction	Mindful Movement practice, Mindful Walking Practice. Working with distraction, Settling Grounding and Resting with the support of Breath
5	Exploring the Undercurrent	Noticing the undercurrent, Loving Kindness practice for other practice
6	Exploring the Attitude of the Observer	Reflecting on the undercurrent, Noticing Attitude practice, being kind to ourselves. Loving Kindness for Self and Other practice
7	Acceptance and Self Compassion	Acceptance- two arrow sutra, R.A.I.N practice, Self-Compassion Break. Three Emotion systems
8	Mindfulness Based Life	Mindfulness Support Revisited. Reflection on the Journey so far

Table 6: Mindfulness-Based Stress Reduction Course

Week	Title of Week	Practices and subject matter
1	Introducing Mindfulness	Introduction to mindfulness, one mindful daily activity. Body Scan and Mindful Eating practices
2	Perception	Mindfulness of Breathing, Pleasant Experiences Diary
3	Mindfulness of the Breath and Body in Movement	Focusing on Breath, Mindful Yoga, Mindful Walking, Awareness of unpleasant experiences.
4	Learning About our Patterns of Reactivity to Stress	Sitting Meditation, Staying present, Stress reaction cycle
5	Coping with Stress: Using Mindfulness to Respond Instead of React	Responding with Mindfulness in Daily Life- thoughts, bodily sensations, awareness of surroundings. Day Silent retreat
6	Stressful Communication and Interpersonal Mindfulness	Mountain Meditation, mindful communication
7	Lifestyle Choices: How can I Best Take Care of Myself	Concentrating on nourishing activities, Being aware of moments of difficulty. Recognising stress indicators
8	Keeping your Mindfulness Alive	Keeping Mindfulness going. Daily Mindfulness