# THE DEVELOPMENT OF DEATH COMPETENCY IN HEALTHCARE PROFESSIONALS: THE ROLE OF PATIENT DEATH EVENT APPRAISAL

College of Health, Psychology and Social Care

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### PREFACE

I declare that the contents of this thesis, submitted for the degree of Doctor of Philosophy entitled 'The Development of Death Competency in Healthcare Professionals: The Role of Patient Death Event Appraisal', is my own work conducted between 2019 and 2023 at The University of Derby.

All work presented in this thesis is original unless stated otherwise in the text or by referencing. All sources have been acknowledged and cited where required. All intellectual property (unless otherwise owned) including texts, tables and images contained within this thesis remain the exclusive property of the author and may not be used without permission. This thesis has not been submitted for any other degree, award or purpose.

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# LIST OF ABBREVIATIONS

| EoL doula | End of life doula                            |
|-----------|--|
| CPR       | Cardiopulmonary Resuscitation                |
| DNACPR    | Do Not Attempt Cardiopulmonary Resuscitation |
| FEoD      | First Experience of Death                    |
| HCP       | Health Care Professional                     |
| IPA       | Interpretative Phenomenological Analysis     |
| ITU       | Intensive Therapy Units                      |
| MMPD      | Most Memorable Patient Death                 |
| NHS       | National Health Service                      |
| PoMS      | The Abbreviated Profile of Mood States       |
| PTSD      | Post Traumatic Stress Disorder               |
| SAM       | Stress Appraisal Measure                     |

#### ABSTRACT

This thesis focuses on the development of death competency – a person's skills and capabilities in dealing with death as well as their beliefs and attitudes about these capabilities (Robbins, 1994) - in healthcare professionals working in both traditional roles (doctors and nurses) and non-traditional, emerging roles (end of life doulas). Death competency is a highly relevant attribute for individuals for whom dealing with death is part of their professional role. It has been argued that death competency development is an ethical imperative due to the demonstrated negative effects of low death competency, namely burnout, compassion fatigue and poor-quality patient-practitioner communication (Chi Ho Chan, 2015; Gamino & Ritter, 2012). As experiencing a death event can be considered a stressful life event, and that responses to a death event may depend on individual appraisal of the event (Kessler, Heron & Dopson, 2012), this thesis explores the role of appraisal of early-career death events and looks at how these appraisals, and subsequent levels of death competency, differ between professional roles.

The studies contained within this thesis begin with a systematic review and metasynthesis of existing literature related to psychological factors influencing healthcare professionals' responses to early career patient death events, followed by a mixed methods study which generated qualitative data and quantitative data via an online survey. Qualitative data collected concerned participants appraisal of their first experience of a death event, quantitative data collection involved a measure of appraisal of these events and a measure of death competency. Survey participants were doctors, nurses and end of life doulas working in the UK.

Method triangulation (Polit & Beck, 2012) was used to bring together findings from the three phases of studies – meta-synthesis findings, qualitative data analysed using template analysis, and a multiple regression used to analyse quantitative data to explore possible predictors of death competency. A reflexivity chapter is presented to explore the role of the researcher as an 'insider-researcher' from a practising end of life doula perspective. Key findings were as follows: controllability and challenge aspects of event appraisal were recurring themes throughout the data suggesting that these may be beneficial areas for future research; professional role affected individual appraisals of patient death events and end of life doulas had higher death competency when compared to traditional healthcare roles. Finally, the insider-researcher position provided a unique angle enabling a detailed exploration of possible practice implications of this thesis' findings including the potential benefits of incorporating aspects of end of life doula training into training for doctors and nurses working in roles which involve supporting patients at the end of life.

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# **CHAPTER 1: INTRODUCTION AND BACKGROUND**

#### 1.1 Overview

This chapter sets out the context for this thesis within the death studies and psychological appraisal fields and introduces key concepts central to this PhD including death competency, death anxiety, death literacy and event appraisal along with professional contexts namely doctors, nurses, and end of life doulas. The rationale for the studies contained within this PhD are outlined and finally the overarching aims and objectives for this PhD are introduced.

### 1.2 A History of Death Attitudes Research

Research into individual death attitudes, often focusing on fears around death and dying, emerged in the late 1950s and 1960s, with ground-breaking contributions regarding fear of death (Feifel, 1956, 1959), grief, fear, and denial (Kubler-Ross, 1969) and death awareness, anxiety, and avoidance (Glaser & Strauss, 1965), laying a foundation for this field. Many studies at this time were based on psychodynamic principles, most notably the idea that peoples' beliefs and fears about death and dying were unconscious and required indirect exploration techniques such as word association and imagery (Neimeyer, 2015). The development of the first quantitative research instruments, including the Collett-Lester Fear of Death Scale (Collett & Lester, 1969), Death Anxiety Scale (Templer, 1970) and the Threat Index (Krieger, Epting & Leitner, 1975), resulted in a temporary "publication explosion" in the late 1970s (Neimeyer, 2004). By 1980, there was a plateauing of interest in death anxiety followed by a decline (Neimeyer & Van Brunt, 1995), with prominent death scholars such as Michael Simpson highlighting that our understanding of death and dying attitudes was being limited by the purely quantitative rating systems and categorisations being used (Simpson, 1980). Simpson (1980) also argued for a move away from the focus on death anxiety to broader and more positive concepts such as death competency.

The emergence of palliative care as a medical specialty in the 1990s brought with it the development of new theories and empirical studies on death attitudes and anxiety which broadened the focus of the field from unconscious, psychodynamic theories of death anxiety, to exploring how real-world events can cause collective increases in death threat and subsequent effects on behaviour (Borgstrom & Ellis, 2017). An increase in research was also driven by the creation of the three specialist death and dying research journals - *Death Studies, Mortality,* and *Omega,* and an increasing public awareness of threats to mortality and health, such as terrorism and the AIDS pandemic (Neimeyer, 2004). This continues today with the current Covid-19 pandemic also prompting a wave of new research into death anxiety (Menzies & Menzies, 2020; Menzies, Neimeyer & Menzies, 2020; Pradhan, Chettri & Maheshwari, 2022; Yildirim & Güler, 2021).

In Neimeyer's (2015) death anxiety handbook which summarised research into death anxiety and death competency to date, he concluded that qualitative evidence regarding healthcare providers' death anxiety and death competency, and specifically the impact this may have on their own wellbeing and the quality of care they provide, is needed to inform improvements in end of life care (Neimeyer, 2015). Despite this call, recent contributions to death anxiety and death competency methodology remain predominantly quantitative, with research focusing on improving existing measures for example development of the Revised Death Anxiety Scale (Thorson & Powell, 2015) and the Coping with Death Scale Short Version (Galiana et al., 2019). A recent review of 21 existing death anxiety measures suggests that further research is needed to conclude the adequacy of these instruments, particularly considering the increased use of these in both clinical and research settings (Zuccala et al., 2022), with some going so far as to state that there is currently no comprehensive, psychometrically adequate measure of the construct (Menzies et al 2022).

At the time of his consolidation of research into death anxiety and competency, Neimeyer reported that no studies into death anxiety and death competency had utilised purely qualitative methods (Neimeyer, 2015), nor had they combined the benefits of both qualitative and quantitative methods, which are discussed in greater detail in this thesis in Chapter 2: Methodology. Since this publication, a small number of studies have used qualitative and mixed methods methodologies (Draper et al, 2019) exploring the topics of death anxiety in cancer survivors using semi-structured interviews (Lim et al., 2022), death anxiety and post-traumatic stress disorder using a mixed-methods questionnaire (Hoelterhoff & Chung, 2017) and death anxiety and patient-practitioner communication (Clare, Elander & Baraniak, 2020; Rodenbach et al., 2016). Neimeyer's conclusion that more diverse and creative experimentation with alternative methods is required in the field of death anxiety and death competency is still applicable today (Neimeyer, 2015).

# 1.2.1 An Introduction to Terminology

Throughout this existing literature, three terms are used to describe an individual's lack of confidence, competence, or ability to deal with the topic of death anxiety. Whilst these terms are sometimes used interchangeably, they are distinct concepts which it is important to clarify at this stage.

Firstly, 'death anxiety' can be defined as "anxiety related to anticipation and awareness of death, dying and nonexistence, including cognitive, emotional, and motivational components that vary according to development and experience" (Lehto & Stein, 2009, p. 32). 'Low death anxiety' has sometimes been used in place of 'high death competency', however they do not hold the same meaning. A person can be high in death anxiety, yet still be death competent, provided they are aware of their anxiety and take steps to overcome this and to avoid it having a negative impact on themselves and those around them if they are working in a role supporting others who are dying (Clare, Elander & Baraniak, 2020).

Secondly, 'death literacy' is defined by Noonan et al. (2016) as "a set of knowledge and skills that make it possible to gain access to, understand, and act upon end-oflife and death care options". It is primarily concerned with information and know-how which can be taught, and which develops through hands-on experience with death and dying, and is broader than just an individual, as one of the four features of death literacy is social action, along with knowledge, skills, and experiential learning (Noonan et al., 2016).

Finally, 'death competency' is defined as 'a range of human skills and capabilities in dealing with death, as well as our beliefs and attitudes about these capabilities' (Robbins, 1994). It is used to describe an individual's ability, rather than collective ability. It also goes beyond knowledge and skills to consider a person's attitudes, recognising that simply having knowledge about death and dying is not necessarily

sufficient for the person to feel confident in dealing with this topic or supporting others.

#### 1.3 Death Anxiety and Death Competency

The underlying premise of death attitudes research to date is that death anxiety is at the heart of the 'human condition' and our fears (Menzies & Menzies, 2020). As far as we know, humans possess a unique combination of cognitive abilities including self-awareness and abstract thought which allow them to understand that one day they themselves will die (Burke, Martens & Faucher, 2010). This knowledge can be described as 'mortality salience', and it brings with it associated distress, which is in turn known as 'death anxiety'.

It could be argued that we are a death anxious society, and much of this is due to significant changes in where death occurs over the past 100 years. In the 1900s approximately 80-85% of deaths occurred in the home (Department of Health, 2008), 50% of deaths occurred at home by the mid-twentieth century, and today the majority of deaths occur in hospital environments (Department of Health, 2008; ONS, 2021). As death and dying have moved 'behind closed doors' we have become detached from the process of dying and lost the knowledge and skills that our predecessors had to deal with this, and what was once viewed as a natural end process to life is now considered a failure in the medical field (Despelder & Strickland 1990). It is not routine for people to talk about what a human dying process looks like. This sets us up for either not being familiar with death at all, or if we do witness death, we may have understandable misunderstandings about what we have witnessed. Many 'symptoms' of a human dying process are easy to misinterpret and can feed into a traumatic narrative of the event, complicating grief, and increasing death anxiety (Mannix, 2018).

Death anxiety is closely aligned with the concept of 'death threat' coined by Kelly (1955), and indeed there are many terms for what can be more simply be described as this – knowing we are going to die causes humans' anxiety and as a result, they are driven to engage in both conscious and unconscious means of coping with this knowledge. Common examples of death anxiety coping strategies are denial, avoidance, and distancing. Whilst it may seem intuitive that avoiding thinking and

talking about death is a good thing, the evidence suggests that it is not, as good quality end of life care relies on good quality communication about death and dying between healthcare professionals (HCPs), patients and those close to the patient such as family and/or informal carers (Black, 2007; Schmidt-RioValle et al., 2012). A more detailed discussion of coping follows later in this chapter.

The evidenced negative effects of death anxiety in HCPs include reduced confidence in discussing end-of-life care with patients and families (Braun, Gordon & Uziely, 2010), avoidance of end-of-life conversations with patients (Braun, Gordon & Uziely, 2010; Ciakowska-Rysz & Dzieranowski 2013; Clare, Elander & Baraniak, 2020; Eggerman & Dustin, 1986), delayed end-of life planning (Reid et al., 2013) and reduced collaboration with other HCPs regarding patients' advance directive needs (Black, 2007). Such avoidance behaviour has been found to be strongly correlated with burnout (Melo & Oliver, 2011), and avoidance of conversations regarding death and dying by health workers in hospital settings has been identified as a significant obstacle to provision of high-quality end-of-life care (Reid et al., 2013). Negative impacts also extend beyond the HCP themselves, as poor end of life communication by HCPs is associated with family distress and increased intensity of patient treatment (Curtis et al., 2016). This is no minor issue, in fact HCPs attitudes to death and their fear and avoidance of issues related to death have been cited as major barriers in the development of global palliative care (World Health Organisation, 2014, 2018).

This avoidance and distancing from dying patients has been theorised to be a coping strategy for HCPs low levels of death competency. Death competency is a highly relevant attribute for individuals for whom dealing with death is part of their professional role, to the extent that it has been argued that death competency development is an ethical imperative due to the demonstrated negative effects of low death competency – burnout, compassion fatigue and poor-quality patient-practitioner communication (Chi Ho Chan, et al., 2015; Gamino & Ritter, 2012). Death competency can protect against compassion fatigue and burnout (Sanso et al., 2015), and the benefits extend beyond the HCP themselves, as previous research has found that HCP who are competent in dealing with death provide more effective patient care (Robbins, 1992; Schmidt-RioValle et al., 2012), are more likely

to collaborate effectively with other HCPs, make timely referrals for patients and engage in advance planning (Black, 2007; Reid et al., 2013).

#### 1.3.1 Why Focus on Death Competency?

By researching the promotion of death competency rather than the reduction of death anxiety we can focus on positive trait development. As Bluck et al. (2008, p. 527) noted "low death anxiety is not a truly positive gain but a reduction in a negative state". Most research to date has focused on the negative effects of high death anxiety in HCPs, the researcher argues that we are at a stage where the focus needs to shift to promoting high death competency for several reasons. Firstly, some level of death anxiety is not only normal but an inevitable part of the 'human condition', we do not have a set 'amount' of death anxiety which is 'normal' and it is problematic and potentially ineffective to attempt to reduce death anxiety across groups of people - there is unresolved debate about 'how high is too high and how low is too low?' (Kasterbaum, 2000). We do know however that people can potentially overcome the negative effects of their death anxiety through being selfreflective (Clare, Elander & Baraniak, 2020) suggesting that the key factor may not be how death anxious the person is, but to what extent they attempt to become death competent regardless of this. Kasterbaum (2000) proposes that research needs to shift to focus on how individuals' function, respond and behave, in situations relating to death. It could be viewed as somewhat nonsensical to focus purely on reducing death anxiety when we have no way of knowing what a 'successful' reduction looks like as this will vary between individuals and will depend on context, culture, individual coping mechanisms and a person's own beliefs about death. Alternatively, if we focus on promoting positive traits of death competency, this is likely to reduce death anxiety and increase HCPs' confidence in providing end of life care (Neimeyer, 2015) but also, importantly, it is likely to have a tangible positive impact on the person and those they are supporting as death competency measures involve outward facing behaviours which benefit others (Galiana et al., 2019).

In summary, reducing death anxiety does not necessarily result in the person then developing their skills and capabilities in dealing with death and dying, whereas developing death competency is more likely to also reduce death anxiety as such development involves both learning coping skills and exposure. This is in line with the rationale presented by Robbins (1994) who first defined the concept of death competency and suggested that interventions based on active participation by the HCP to increase death competency were likely to result in more successful outcomes than interventions aiming to reduce fear or anxiety (Robbins, 1994).

The more positive framing of offering support for people to develop their competence rather than reduce their anxiety may also mean that HCPs are more receptive to such interventions and may avoid any messaging which could be interpreted as blaming HCPs. Understanding the development of death competency could enable us to identify areas where training and support are required, and where intervention would be most beneficial. If we know what factors facilitate and promote the development of death competency, we can then provide more focused support to minimise the negative effects of death anxiety on HCPs, such as burnout, and on patients' quality of care, in the form of avoidance of discussion regarding the patient's wishes and prognosis.

### 1.3.2 Death Competency and Death Literacy: what is the difference?

Death literacy encompasses several types of knowledge – practical, experiential, factual and community knowledge. Death literacy draws on a community development framework to inform ways that groups of people (communities) can improve their ability to support those within the community with matters relating to death and dying (Noonan et al., 2016). Death literacy has been recognised as a necessary skill for HCPs in acute care settings (Mulcahy, 2018).

As we have seen when exploring existing research into death anxiety and death competency, focusing purely on a person's knowledge and practical skills around death and dying means we miss an important part of the bigger picture – their own attitudes and feelings regarding death and their own mortality, and their coping strategies for their death anxiety. A person can have a great deal of knowledge about how to deal with death and dying, but if their own death anxiety and coping strategies (such as avoidance) get in the way of them engaging with others meaningfully around this topic, they are still not going to be able to provide quality support to others.

Death competency refers not only to what a person knows about death and dying but their ability to acknowledge, explore and overcome their own death anxiety. If we are to research ways of better supporting HCPs to provide high quality end of life care, the researcher proposes that alongside the focus on developing death literacy, we need equal effort directed towards identifying how HCPs develop death competency and what factors can facilitate this. This is in-keeping with the General Medical Councils recommendations for medical students training in the UK, which acknowledge the importance of facts and knowledge, but highlight the need to consider HCPs own attitudes and instruct medical schools to aim to support medical students in overcoming their fears around death and dying (Gibbins et al., 2010).

#### 1.3.3 Death Competency: What do we know so far?

We know that death competency involves a combination of professional skills and behaviours, along with self-awareness of one's own attitudes towards death and dying, meaning it is distinct from many other professional competencies (Cheung et al., 2018).

With the majority of existing research into death anxiety and death competency focusing on the reduction of death anxiety rather than the development of death competency (Neimeyer, 2015), to date there have been no studies focusing on the process of death competency development, with existing theories based on Bandura's (1977, 1982, 1986) social learning theory predicting that individuals may develop death competency via imitation, modelling and active participation (Robbins, 1992). Bandura used the term perceived self-efficacy to refer to an individual's confidence and capacity to perform a certain behaviour successfully (Bandura, 1977). This concept is closely aligned with that of death competency as this refers to an individual's self-efficacy for dealing with death and dying. In the context of HCPs this development, based on Bandura's theory, would involve the individual seeing their colleague supporting someone at the end of life, then in turn providing support themselves, and this resulting in increased self-efficacy for providing this support in the future.

Previous research has found that older age (in these studies defined as aged 50 or above), finding meaning in life (Miller-Lewis et al., 2019) and previous bereavement

experience were positively correlated with death competency (Chan et al., 2015; Cheung et al., 2018). There have also been contradictory results regarding correlates of death competency with Chan et al. (2015) and Ober, Granello & Wheaton (2012) reporting that experience in roles which involved supporting others with death and dying ('death work experience') significantly predicted death competency, however Cheung et al. (2018) found no significant relationship between these variables. These conflicting results may be in part due to methodological limitations, as Cheung et al. recruited participants who were attending workshops and seminars on death and dying who may already have been more death competency self-report methods as participants may want to be seen as competent professionals (Chan et al., 2015; Cheung et al., 2018).

Existing research has concluded that qualitative studies should be conducted to investigate factors underlying death competency development and explore how this relates to HCPs' experiences, as such factors need to be considered in the design of any future interventions which may aim to improve staff death competence (Cheung et al., 2018).

#### **1.4 Death Competency and Professional Roles**

A further factor which must be considered when studying the development of death competency is the professional role a person holds and what expectations, motivations, and priorities this brings with it. For example, an individual working in a 'traditional' medical role such as a doctor or nurse supporting a dying patient, may be more likely to focus on continued treatment, taking action and prolonging life as opposed to a patient's emotional needs, desire for honest communication regarding prognosis and acceptance that the person is dying – this has been referred to as a 'cure vs care' focus (De Valck et al., 2001; Ong et al., 1995).

When considering professional roles in relation to death competency, at one end of the scale there are roles which hold no expectation that the person will bring a personal perspective on death and dying, and the role does not involve exposure to death and dying. At the other end of the scale some roles, for example hospital chaplains or funeral directors from a specific faith, come with an expectation that the person will a) hold a strong personal perspective on death and dying, b) will understand wider perspectives and worldviews on death and dying and c) integrate the two to provide counsel to others regarding death and dying. In between these two extremes are the roles central to this thesis, such as that of doctors and nurses, who are exposed to death and dying in their role, expected to provide 'counsel' (in this case medical advice) regarding death and dying, but they are not a) asked to bring their personal perspective on death and dying to the role and b) are not provided with an overarching worldview of death and dying as part of their training for the role.

#### 1.4.1 Traditional Healthcare Roles

This can create difficulties particularly for HCPs working within a healthcare system driven by the three goals of clinical medicine – prevention, cure/restoration, and maximising quality of life (Zubialde, Mold & Eubank, 2009). As Kasterbaum explains "[healthcare professionals'] personal perspective may coexist uneasily with the timepressured functionalistic approach that is characteristic of health service delivery" (Kasterbaum, 2000, p. 211). There is also an ingrained and enduring attitude that death equals failure in hospital settings - Rhodes-Kropf et al. (2005) found that medical students were consistently given the message that a physicians' focus was on maintaining life through interventions and that they had failed if patients die (Rhodes-Kropf et al., 2005). Indeed, many aspects of good quality end of life care require HCPs to act in a way that contradicts the 'medical mandate' which is has a clear, central goal of restoring patients to health (Meliones, 2000; Peters et al., 2013). When combined, these factors result in situations where doctors and nurses are required to act in ways, when confronted with patient death, that may not fit with their own views, emotions, and goals, causing distress to themselves and negative impacts for patients such as the continuation of futile treatment (Peters et al., 2013).

Traditional healthcare roles are built on the biomedical model of disease, and an authoritarian relationship between the expert HCP and patient as a passive recipient of treatment (De Valck et al., 2001). This approach has many benefits as it is scientific and based on objective medical data, however it is also known to reduce the patient to their diagnosis and neglect their emotional, functional, and social health needs (De Valck et al., 2001).

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This is somewhat understandable since patients look to doctors and nurses for answers and factual information regarding their health status (Ong et al., 1995), and that medical training has a curative focus resulting in what has been described as 'dehumanisation' during medical training (De Valck et al., 2001). Previous research has found that medical students find it difficult to integrate care attitudes with cure attitudes taught during their training, in part due to emotional detachment being encouraged from early in medical school (De Valck et al., 2001; Horne et al., 1990) resulting in growing cynicism and loss of humane attitudes toward patients as they progress through training (Brock et al., 1992; Rezler & Haken, 1984; Wolf et al., 1991).

To enable exploration of the potential differences in death competency between those working as doctors and nurses, and those working in other 'non-traditional', more contemporary and recently emerging roles, the terms traditional and nontraditional healthcare roles will be used from here on in this thesis.

# 1.4.2 Can we Learn from Non-Traditional Roles? End of Life Doulas

The word 'doula' comes from the Greek 'woman caregiver' (Campbell, et al., 2006, p. 456) and was popularized by the natural birth movement in the 1970s (Krawczyk & Rush, 2020), however this meaning has been extended over time and now is used in the context of support in several major life transitions and events, including Birth Doulas, End of Life or Death Doulas and Abortion Doulas in countries around the world (Chora, et al., 2016). A systematic review in 2019 highlighted the range of terms used to describe the doula role, including death midwife, soul midwife, amicus mortis and lay navigator (Rawlings et al., 2019). The term End of Life Doula (EoL Doula) has been accepted by those working in the field at an international level as demonstrated by the title and outcome report from the first International End of Life Doula Symposium held in 2022 (Krawczyk, et al., 2022) though is it still used interchangeably with the term 'Death Doula'.

A shared aim across all doula roles relates to the filling of gaps in existing care and being alongside, and complementary to, other health and social care professionals. EoL Doulas provide practical, emotional, and spiritual support to individuals with a life-limiting illness and those important to them (End of Life Doula UK, 2022). The

focus is on developing a relationship with the person being supported, and the role varies depending on the patient's needs (Nelson, 2015). This can include explaining the dying process, advance planning, reducing anxiety, respite care, grief support and funeral arranging (Wolfson, 2014). In contrast to traditional healthcare roles "an EoL doula's role is focused on the act of being, not doing or fixing... the EoL doula does not enter into the experience with a pre-set agenda" (Trzeciak-Kerr, 2016, p.8) and by "just being" can learn about a person beyond his or her diagnosis (Altman, 2014a; Altman, 2014b). An EoL doula does not need to be medically trained as the focus of their role is on companionship and advocacy (Shira Ruskay Center, 2008). Hermione Elliott, Director of Living Well Dying Well, who founded and developed EoL doula Training in the UK, in her paper 'Beyond the Medical Model' explains that EoL doulas add a 'missing layer' between existing medical expertise and form the foundations of a more sustainable, community focused way of supporting people at the end of life (Elliot, 2011). This has recently been recognised by 'mainstream' health and social care organisations with The Lancet report 'The Value of Death: Bringing Death Back into Life' concluding that by maintaining a flexible role, EoL doulas are ideally placed to 'fill gaps' in existing services, gaps which have been made clearer and wider by the Covid-19 pandemic and ongoing pressures on community end of life care services (Sallnow et al., 2022).

To date there is very little existing research about EoL doulas, with the exception of some notable academics who frequently publish on the topic such as Deborah Rawlings, who is based in Australia. Rawlings' systematic review in 2019 entitled 'What role do Death Doulas play in end-of-life care? A systematic review' found five existing articles – three narrative pieces, a dissertation, and a published peer-reviewed article - describing the role of an EoL doula. Four out of the five articles were judged to be of 'limited' quality as they included commentary only and no formal analysis. Rawlings et al. (2019) found that there were disparities between how the EoL doula role is enacted across different counties, for example the contrast between a paid vs volunteer role, overlap with medical roles vs a clearly defined non-medical role, and wide variation in terms of training programmes. The review concluded that "this systematic review has revealed a dearth of published academic literature about death doulas in end of life care...further research into the role played by death doulas is sorely needed" (Rawlings et al., 2019, p.e91). In 2016 Trzeciak-

Kerr reported that studies involving EoL doulas had been limited to nursing, palliative, and hospice journals and had not been conducted within the field of psychology (Trzeciak-Kerr, 2016), this continues to be the case (Rawlings et al., 2021). Studies to date have concentrated on defining and describing the role of an EoL doula, with only one formal empirical study identified in Rawling's 2019 literature review – an unpublished PhD thesis using qualitative methodology to explore the lived experiences of EoL doulas working in the role and those who have received EoL doula support (Trzeciak-Kerr, 2016).

EoL Doula 'movements' are most evident in Western countries, namely the UK, Australia, USA, and Canada, where EoL doula national organisations have developed and grown. All have reported increased demand for training fuelling a move towards development of competencies (Krawczyk et al., 2022) and attempts to sure-up ways of working more formally alongside existing health and social care services, without 'diluting' the unique nature of the EoL doula role. This has both been made possible by, and in turn driven a further need to clearly define the EoL Doula role in the UK, to increase the quality and credibility of training qualifications and further the perception of the role as a viable paid occupation. When compared with the results of the Rawling et al.'s review, this makes the UK an ideal context to study the EoL doula role as the discrepancies which are present in other countries are far less apparent in the UK, largely due to the existence of End of Life Doula UK, the Membership association for EoL doulas which sets clear standards for the role (End of Life Doula UK, 2022).

EoL doulas in the UK have, due to the increased strain on community services during the Covid-19 pandemic, been invited to work more closely with existing services over recent years, and this PhD has taken place during a time when the acceptance of the EoL doula role by health and social care professionals in the UK is at an all-time high. This is demonstrated by the fact that End of Life Doula UK were commissioned by Leeds Integrated Care Board (ICB) to provide EoL doula support to the Leeds population in 2022 and that information and outcomes from this project are being shared in publications such as the British Medical Journal (Howard, 2022).

Whilst medical professionals and EoL doulas often end up supporting people through the same terminal diagnosis, their training journey to that point is vastly different. While medical training focuses on teaching information so that doctors and nurses can have the answers, EoL doula training spends a considerable amount of time teaching doulas to be comfortable with feeling at home in the unknown (Elliott, 2011) with a focus on curiosity rather than expertise (Wolfelt, 1999). Of course, there are benefits to both approaches – it is vital that doctors do have answers. However, when it comes to death and dying, there are always unknowns, and sometimes striving to provide answers can cause unnecessary distress both to the HCP themselves and those they are caring for (Mannix, 2018).

In contrast to this, EoL doulas' training is built around the idea that death is a natural part of life, that an EoL doula is not there to prevent the death or to 'fix' or 'rescue', only to accompany and support. The focus is primarily on 'being' rather than 'doing'. EoL doulas are specifically trained in each aspect of death competency and for this reason, this makes them an interesting subject for this thesis.

### 1.4.3 The Researchers Role

To set the context for this PhD, it is important to introduce the researcher's role in relation to EoL doulas. The researcher is both a practising EoL doula, and Director of End of Life Doula UK – the UK membership organisation and community of practise for EoL doulas. Due to the researcher's dual roles of both researcher and practitioner, in addition to the qualitative nature of the methodology used in this PhD, researcher reflexivity is a vital part of the research process to ensure transparency, and enhance the quality, rigor and ethics of the studies contained within this PhD (Davis, 2020). For this reason, a dedicated chapter on reflexivity is included at the end of this thesis: Chapter 5: Reflexivity.

# 1.5 How to Study Death Competency

# 1.5.1 Early Career Death Events

Although patient death can be viewed as an expected part of the job for HCP research suggests that these events are far from mundane, everyday experiences. Whilst this does depend on the field of medicine that the HCP is working in, with death and dying being a central focus of palliative medicine for example, existing literature has explored HCPs' experiences of patient deaths in fields of oncology

(Granek et al., 2015, 2016, 2017), paediatrics (Lima et al., 2018) surgical nursing (Thompson, Austin & Profetto-McGrath, 2010), internal medicine (Good et al, 2004), community nursing (Mast & Gillum, 2018) and physiotherapy (Powell & Toms, 2014). Such research has consistently found that patient deaths can have a significant impact on HCP no matter their speciality.

Some patient death events appear to be especially memorable, recalled in greater detail than others, and having a lasting impact on the HCP themselves. The most significant patient death experiences often occur early in a HCPs' career (Schulz-Quach, 2018) with studies suggesting that the often negative impact of these events is due to a number of both professional and personal factors including lack of preparedness and training, inadequate support, having no prior experience of death and dying, and a combination of these factors in addition to the traumatic nature of the death events making them especially memorable and formative (Anderson, Kent & Owens, 2015; Bharmal et al., 2022). Early career patient death events have been found to impact the future care the HCP goes on to provide to other patients (Gerow, et. al., 2010; Zust, 2006). Negative early career patient death experiences can cause HCPs to experience physical and psychological symptoms such as sleeplessness and re-experiencing the event (Anderson, 2015) and can even cause HCPs to choose a different medical field to avoid dealing with patient deaths in the future due to the personal impact on themselves and/or witnessing the impact on their colleagues including burnout and compassion fatigue (Anderson, 2015; Granek et al, 2015). This impact extends beyond the HCP themselves, with negative impacts for patients particularly if the HCP goes on to avoid future death and dying related conversations and situations as a coping strategy (Black, 2007; Braun, Gordon & Uziely, 2010; Ciakowska-Rysz & Czarnowski 2013; Clare, Elander & Baraniak, 2020; Eggerman & Dustin, 1986; Reid et al., 2013; Viswanatham, 1996).

It has been repeatedly recognised in recent decades that nurses' first experience of a patient's death can have a significant and lasting impact on their future practice by leading to feelings of helplessness, defensiveness, and distress, resulting in coping strategies such as distancing, emotional suppression, and avoidance (Anderson, Kent & Owens, 2015). Recent research has recommended that, due to the significance of nurses' first experience of a patient death, future research should identify indicators

which can be tracked to promote the development of relevant competencies (Gorchs-Font et al., 2021).

It is important that these personal and professional impacts are considered when planning educational and training interventions for HCPs. Schulz-Quach (2018) highlighted the need for us to further our understanding of the impact of these patient death events, saying "I have yet to meet my first hospice and palliative care peer who did not have some form of significant death encounter prior to their decision to turn towards dying and death as a professional career. The literature about this and our own professional discourse about how death affects us and how it shapes our experience is limited, at least" (Schulz-Quach, 2018, p. 303).

Whilst career stage has a clear impact on how HCPs experience patient death, HCPs' responses to patient death varies between individuals, as we all experience different responses to the same event due to our different evaluations and interpretations of what happened (Hwang, 2006). The lack of research into HCPs' ways of dealing with death and dying has been described as a "striking neglect", and recent studies have turned to event appraisal theories to study HCPs' individual emotional responses to death as an event (Kessler et al., 2012).

# 1.5.2 How to Study Death Competency: Death as an Event

Death may seem like a clear-cut concept however our definition is shaped by our society and beliefs and there is much disagreement between academics and philosophers about how to define it (Youngner & Arnold, 2001). A debate has been ongoing since it first began in the academic domain with Robert Morison and Leon Kass, who argued over whether death was a process or an event (Morison, 1971; Kass, 1971). Advances in medical technology have driven a need to reconceptualise death. Prior to the 1970s the only medical criterion used to certify death was the cessation of cardiopulmonary function, however with the invention of artificial ventilation, it was necessary to revaluate what it meant to be dead as there were patients who did not have any active brain function but whose cardiopulmonary function continued, resulting in the adoption of the concept of 'brain death' (Youngner & Arnold, 2001).

If we think about traditional definitions of death, found throughout our culture, death is a "clearly defined event, a step function that puts a sharp end to life" (Morison, 1971, p. 694). From a medical and legal point of view, death is an event – a person is alive, death happens, and then they are "declared dead". It is necessary for communication and medical recording that it is possible to identify 'points of no return' regarding death events with the most obvious being the cessation of circulation and the cessation of brain activity – both clinical measures of whether death has occurred (Gardiner et al., 2012).

Having said this there is clearly more to death that the moment of death itself. Robert Morison (1971) said that death is "no more a single, clearly delineated, momentary phenomenon than is infancy, adolescence, or middle age" (Morison, 1971, p.694). Except for instantaneous (such as that in an accident or act of war) death, death is part of a longer process which we refer to as dying. This involves recognisable 'symptoms' as the human body ceases various functions which is sometimes referred to as 'normal' or 'natural' dying by those who aim to increase knowledge of the process (Mannix, 2018). This is linked to the concept of death as a failure of medicine – by focusing on death as a process rather than an event, this may appeal to medical professionals as a process provides multiple opportunities for them to intervene and provide support, and more opportunities for them to have control over the situation (Morison, 1971).

Others have challenged the definition of death as a process, arguing that "attempts to blur the distinction between a man alive and a man dead are both unsound and dangerous" (Kass, 1971, p.1). This topic and debate is far larger than can be fully explored here, however one part that is central to this thesis is whether we are viewing death as an event or as a process. Perhaps the answer is to recognise that death is both – a dying process ending in a clearly defined moment of death event. For us to be able to study how people, in this case HCPs, experience patient death it is necessary for us to clarify the definition used in this study. If we were to focus purely on the process of dying, without the death event at the end of this, the focus would be shifted to end of life care rather than the impact of the event itself. Therefore, for the purposes of this PhD, as we are exploring event appraisal, death (specifically patient death) is defined as an event at a point in time.

# **1.6 Appraisal Theory and Coping**

Arnold (1960) suggested that for a person to experience an emotion, they must judge the object of their emotion as affecting them personally in some way. This formed the basis of appraisal theory, a large research area in cognitive psychology made up of multiple theories with a similar premise, which arose from attempts to explain the fact that a) different people can experience the same event and have different reaction and b) that the same person can respond differently to the same event depending on the context.

Theories of event appraisal developed through the work of Richard Lazarus and colleagues researching the psychological theory of stress and coping over several years (Folkman et al., 1986) and resulted in the widely accepted transactional model of stress and coping (Lazarus & Folkman, 1984). In short, cognitive appraisal refers to "the process of evaluating or categorising the personal significance of events" (Peacock & Wong, 1990). The transactional model involves two key processes – cognitive appraisal of an event, and subsequent coping – and explains how these mediate stressful interactions between a person and their environment, in addition to the short and long-term outcomes of the event (Lazarus & Folkman, 1984; Folkman et al., 1986).

Cognitive appraisal, according to the transactional model of stress and coping (Lazarus & Folkman, 1984), of an event is split into two phases – primary and secondary appraisal. Primary appraisal involves the individual assessing whether the event poses a risk of harm or benefit to a) their own health or wellbeing b) the health or wellbeing of a loved one c) to their own self-esteem or d) with respect to their own goals. Once this has been assessed, secondary appraisal of the event takes place involving the individual considering whether they can affect the outcome of the event (prevent harm or maximise benefit) and whether they have the tools to cope with the situation (Folkman et al., 1986).

The transactional model of stress and coping also indicates types of coping which may be more likely to lead to poor event outcomes. Coping, which refers to a person's efforts to manage demands that are appraised as taxing or exceeding their resources (Lazarus and Folkman, 1984) occurs alongside appraisal and together these concepts mediate interactions between the individual and their environment and impact the short and long-term outcomes of an event (Folkman et al., 1986). Existing research into coping is a vast field and one which is lacking in consensus regarding the structure of coping, particularly in terms of categorising coping strategies, with over 100 taxonomies and 400 lower-order classifications proposed in the literature as of twenty years ago (Skinner et al., 2003) with a number of significant additions since (Stanislawski, 2019).

Some types of coping are particularly relevant to death anxiety and competency research for example, as we have seen, distancing is a commonly used coping strategy for death anxiety and is associated with unsatisfactory outcomes particularly in situations where the event requires the person to attend to the problem (Katz et al., 1970) such as in a healthcare setting. Distancing and avoidance can be considered forms of 'disengagement coping', a term that refers to coping strategies which attempt to divert away from the stressor and/or subsequent emotional response (Carver and Connor-Smith, 2010). Conversely, engagement coping strategies involve addressing the stressor 'head on', and include problem solving, seeking social support and emotional regulation (Carver and Connor-Smith, 2010) which are associated with more positive outcomes compared to disengagement coping strategies (Buizza et al., 2022; Chao, 2011; Fortes-Ferreira et al., 2006) possibly due to the increased sense of controllability they foster (Carver and Connor-Smith, 2010). The extent to which individual's coping strategies succeed – effective coping - is closely related to competence, as if the individual believes they were able to successfully cope with a similar situation in the past they will be more likely to perceive themselves as competent in dealing with this situation in the future (Liam, 2022).

#### 1.7 Death Competency and the Covid-19 Pandemic

Mortality salience is mindfulness of the inevitability of one's own death (Greenberg, Pyszczynski & Solomon, 1986). Over recent years, collective mortality salience has been increased by the Covid-19 pandemic (Hu, He & Zhou, 2020; Liu, Lv & Tang, 2021; Menzies & Menzies, 2020). With death and dying reported daily on the news (including mortality rates), constant reminders of threats to our lives caused by the virus, and the experience of the significant loss of life caused by Covid-19, we have

all been made more aware of illness and death, resulting in a significant increase in mortality salience and death anxiety (Cable & Gino, 2020; Hu, He, Zhoue 2020; Menzies & Menzies, 2020). This effect was especially pronounced for those working in professions where exposure to death and dying increased as a result of the pandemic, including HCPs who were extended from their usual roles and moved into more acute hospital environments such as intensive therapy units (ITUs) to manage increased need (Ratiu, Curseu & Fodor, 2022).

The Covid-19 pandemic has wrought tragic consequences across the globe, however speaking purely from a research perspective, it has created a unique situation and opportunity. Prior to the pandemic, death anxiety research would use 'priming' techniques to prompt a sense of death threat, however the pandemic created these conditions in a natural, daily, and ongoing way (Menzies & Menzies, 2020). Studies have found that asking participants to think about current epidemics or pandemics have similar effect to such primes by making thoughts about death easier to access and triggering protective behaviours (Arrowood et al., 2017; Menzies, Neimeyer & Menzies, 2020; Van Tongeren et al., 2016). Indeed, there has been a rush of research publications over the past year looking at mortality salience and the Covid-19 pandemic and subsequent effects on human behaviour. The wide range of this research, spanning sign evaluation (Kellaris, Machleit & Gaffney, 2020), HCPs (Ratiu, Curseu & Fodor, 2022) jury decision making (Lucas-Marinelli, 2020) and charitable donations (Jin & Ryu, 2021), mirrors the range of mortality salience research in general with some of the most cited papers on the topic looking at intergroup bias (Hewstone, Rubin & Willis, 2002), political preferences (Landau et al., 2004) and consumer behaviour (Arndt et al., 2004).

It is important to note this context, in which this PhD took place, as this had significant implications for the planning, process, methodology and participants of this study. Many of the participants in this study were HCPs whose roles were changed dramatically by the pandemic. Some EoL doulas were unable to visit patients in person and so moved to providing remote support. Some doctors and nurses were pulled into 'front line' roles where they were far more exposed to death and dying than in their usual roles. All participants were subject to the general increase in mortality salience previously described. Consideration was given as to whether to make this PhD more Covid-19 pandemic focused at the start of the pandemic, when it became evident that this necessitated a re-think to ensure that the topic was still viable and needed at this time. The researcher decided that prior to the pandemic, the subject of HCPs death competency was an important research area, and that the increase in exposure to death and dying due to the pandemic had only increased the need for this research to be undertaken. This decision making process is detailed further in Chapter 2: Methodology.

#### **1.8 Researcher Context: Reflexivity**

In addition to considering the wider context of the Covid-19 pandemic, another important positioning of this thesis related to the position of the researcher, who is both an 'insider' within the population being studied as a practising EoL doula, and an 'outsider' researcher studying this role. It is important to reflect on how this position may influence this thesis and studies contained within it from the outset, to minimise any potential negative researcher effects. In terms of personal stance, the researcher believes that the ethos and training underpinning the EoL doula role results in a valuable and complementary alternative to healthcare services based on the medical model. At the same time, as someone who has worked in NHS roles for much of my career to date and who believes strongly in the ethos of the NHS, this PhD is being undertaken with a personal goal of wanting to support NHS staff in dealing with patient deaths particularly in the current climate where due to the pandemic, along with over-stretched services and a lack of funding, HCPs working in hospital settings are under immense pressure.

#### **1.9 Concluding Remarks**

To revisit our death literacy and death competency definitions – death literacy as 'a set of knowledge and skills that make it possible to gain access to, understand, and act upon end-of-life and death care options' (Noonan et al., 2016) and death competency as 'a range of human skills and capabilities in dealing with death, as well as our beliefs and attitudes about these capabilities' (Robbins, 1994) - it seems that HCPs in the UK either do not receive adequate end of life care training (so are not literate or competent) or they may receive training in a practical knowledge

sense, but which misses addressing their own attitudes and feelings about death and dying (so are literate but do not feel truly competent).

What if we could train and support HCPs to both have the answers when they need to have the answers (much of the time) but to also be comfortable with the unknown when it comes to death and dying, to learn from the EoL doula approach, to be able to 'park' their medical hats and have the human-to-human conversations around death and dying, and crucially, for them to work in a culture which supports this? As we have seen, to identify ways in which HCPs' become death competent, we need to know how they experience, and appraise, patient deaths they experience. If there are differences in death competency between traditional HCPs and EoL doulas, what can traditional medicine learn from EoL doula approaches to inform their own practice?

This study will involve an exploration of how HCPs working within hospital settings appraise patient death events which, to the researcher's knowledge, has not previously been conducted in the UK. The focus on early-career patient deaths and on the individuals' competency for dealing with death and dying also provides a new research angle. The inclusion of EoL doulas in the study is a significant novel contribution to this research area as this is the first EoL doula study of its kind. There are no existing studies investigating how EoL doulas experience the deaths of those they support and how this compares to traditional healthcare roles and this study will identify whether there are fundamental differences in death competency between these roles. The results of this study have the potential to inform interventions to promote development of death competency in HCPs, a trait which we know offers protection from compassion fatigue and burnout (Sanso et al., 2015), and leads to HCPs providing more effective end of life care to patients (Robbins, 1992; Schmidt-RioValle et al., 2012).

#### 1.8.1 Research Question - Aims and Objectives

The overarching aim of this PhD is to explore how HCPs' appraisal of patient death events affect their development of death competency, whether appraisal of such events and death competency differs between traditional and non-traditional healthcare roles and by level of experience, and to identify possible predictors of death competency. A further aim is to provide a reflexive account of the researcher's position as a practising end of life doula whilst undertaking this PhD.

# Objectives

- To systematically review existing literature investigating psychological influences of HCPs' responses to patient death events, including their appraisal and coping strategies
- To conduct a mixed methods exploration of HCPs' narratives of patient death events to investigate their appraisal of such events and their subsequent ability to develop death competency
- To compare differences in patient death event appraisal according to professional training and identity focussing on traditional and non-traditional healthcare roles specifically doctors, nurses, and end of life doulas
- 4. To identify potential predictors of death competency development following first experience of a patient death event
- 5. To reflect on the process of conducting research into HCPs' development of death competency from the perspective of a trained end of life doula

This study asks the research questions "how do HCPs' individual appraisals of patient death events affect their death competency development and does this differ by professional role?" and "what aspects of patient death event appraisal predict death competency development?"

# 1.8.2 Organisation of thesis

This thesis began by outlining existing research relevant to death competency, introducing other related concepts including death anxiety and event appraisal theory and how this can be applied to patient death events. The next chapter will report the findings of a systematic review and meta-synthesis of psychological influences of responses to early-career patient death in HCPs. Chapter 3 will outline the methodology, including the rationale for the choice of methods used in the studies contained within this PhD, and the underpinning ontology and epistemology behind these. A mixed methods study investigating appraisal of early-career patient death

events in doctors, nurses, and EoL doulas is reported in Chapter 4. This thesis also includes a reflexivity chapter which presents the researchers reflection on her role as a practising EoL doula, as both an 'insider' and 'outsider' researcher. Finally, this thesis concludes with full discussion of results including applications to practice and contribution to the field, strengths and limitations of this PhD, and suggestions for future research.

# **CHAPTER 2: LITERATURE REVIEW AND META-SYNTHESIS**

What are the Psychological Influences on HCPs' Initial Reactions and Coping Responses to Early Career Patient Death Events: A Systematic Review and Metasynthesis.

# **3.1 Introduction**

This literature review identifies and assesses existing evidence surrounding how HCPs experience early career patient death events. It identifies key psychological factors which influence HCPs reactions following the death of a patient in their care and their subsequent coping responses.

### 3.2 Review Context and Rationale

To the researcher's knowledge there are no existing systematic reviews investigating this area, with existing systematic reviews focusing on HCPs coping with providing palliative care <u>prior</u> to patient death (Bharmal et al., 2019), focusing on general coping, resilience or stress in end of life care (Gillman et al., 2015; Martins Pereira, Fonseca & Carvalho, 2011; Peters et al., 2012; Powell, Froggatt & Giga, 2020; Zanatta, Maffoni & Giardini, 2020), and only including participants from one HCP role (Wilson & Kirshbaum, 2011; Zheng et al., 2018). In relation to the field of health psychology, there is also a lack of research investigating psychological factors which underlie HCP's means of coping with the patient deaths they experience. As competency, including death competency, is an outcome associated with effective coping (Liem, 2022), it is important for us to begin by establishing what is already known about how HCPs react to and cope with patient death events.

The wider context of the death and dying discourse within healthcare organisations in the UK and beyond also make this a timely review. High profile reports, such as The Lancet Commission on The Value of Death (Sallnow et al., 2022) have recently called for a 'rebalancing' of how we deal with death and dying, pointing to the fact that healthcare systems and cultures themselves do not generally facilitate death being 'done well'. These recent recommendations have built on those made by the government 'Health Profile for England' which stated that high quality end-of-life care provision is "more important than ever" due to the forecast that the number of people aged 65 and over in the UK is expected to rise by 41% between 2020 and 2040 (Mayhew, 2020). Taken alongside the fact that in the UK, deaths are most likely to occur in hospital (Marie Curie, 2013), where high quality end-of-life care is dependent on effective communication between patients, families and HCPs, there is an ever-growing need for research that can improve end-of-life care provision.

## 3.3 Review Background Theory: Appraisal and Coping

Further to the detailed presentation of appraisal and coping theory in Chapter 1: Introduction and Background, it is worth beginning this chapter by recapping these theories as they are central to this literature review.

When a person experiences an event, they engage in a process of cognitive appraisal – that is, "the process of evaluating or categorising the personal significance of events" (Peacock & Wong, 1990, p.1). Cognitive appraisal is followed by coping, which refers to an individual's efforts to manage demands that are appraised as taxing or exceeding their resources (Lazarus & Folkman, 1984). Together, appraisal and coping mediate interactions between a person and their environment and impact the short and long-term outcomes of events (Folkman et al., 1986).

As coping is a broad term for a wide range of individual actions, there have been a vast number of attempts to categorise coping strategies, with a review of these category systems including over 400 coping strategies and 100 categorisations (Skinner et al., 2003). One of the most well-received categorisation recommendations is that of engagement vs. disengagement coping (Carver and Connor-Smith, 2010). Engagement coping refers to strategies which involve facing the stressor 'head-on' to confront the stressor and "take charge", whilst disengagement coping involves strategies aimed at diverting away from the stressor and/or subsequent emotional response, and include avoidance, helplessness and 'palliative reaction' which refers to emotional numbing (Carver and Connor-Smith, 2010). Evidence suggests that engagement coping strategies are more likely to lead to positive outcomes compared to disengagement coping strategies (Chao, 2011; Fortes-Ferreira et al., 2006), and that this may be because they provide the individual with an increased sense of controllability (Carver and Connor-Smith,

2010). Effective coping – the extent to which individual's coping strategies succeed – is closely related to competence, as if the person believes that they were able to successfully cope with a similar situation in the past they will be more likely to perceive themselves as competent in dealing with this situation in the future (Liam, 2022).

### 3.4 Existing Research

There has been an increase in research into HCPs' reactions to patient death over the past 20 years, likely in line with palliative care research, as societies have realised the value of such care (Schenker & Arnold, 2015). This is particularly the case if we look at the literature globally, and it is now possible to explore ways in which HCPs both respond to and cope with patient deaths on an international scale. Previous studies have concluded that further research is needed to identify the responses and needs of nurses when it comes to patient death (Rickerson et al., 2005). An existing review into how nurses cope with patient death (Zheng et al., 2018) found that nurses needed more support, in the form of emotional support, debriefing opportunities and resources, to enable them to cope with patient deaths. Similar findings have been reported regarding doctors, for example Bharmal et al. (2019), who conducted the first systematic review of international literature on trainee doctor's experience of providing end of life care, found that doctors generally felt ill-prepared and inadequately supported.

Previous systematic reviews have identified that most of the research into HCPs' reactions to and coping with patient death focus on dying and the process of dying rather than death (Schulz-Quach, 2018). Whilst a considerable amount of research has been published on the general impact of providing end of life care on HCPs, relatively little has looked at the impact of patient death and how HCPs react to patient death events in the short term as opposed to longer term impacts such as burnout. That which does exist is typical of an emerging research area in that methods are exploratory, and findings are varied, sometimes lacking clarity, resulting in them being described overall as 'fragmented' (Schulz-Quach, 2018), with a common example of this being studies which set out with the aim of investigating reactions to patient deaths but which then broaden the scope of the study to include general experiences of providing end of life care. It would therefore be of use to the

field to pull together existing findings which do relate directly to reactions to patient death in a thorough and systematic literature review.

### 3.5 Research Settings

Most of the existing literature on how HCPs cope with patient death has focused on deaths that occur in palliative care settings as opposed to hospitals (Powell & Toms, 2014). Research in hospital settings is especially sparse despite most patient deaths in high-income countries such as the UK occurring in these environments (Jiang & May, 2021; Powell & Toms, 2014). Previous reviews have found that the setting in which death occurs can influence the experiences of HCPs (Schulz-Quach, 2018) and whilst some aspects of high-quality palliative care can be found in hospital settings, the subject of death and dying is still feared and therefore often avoided in these settings (Clare, Elander & Baraniak, 2020; Powell & Toms, 2014) partly due to a focus on curative measures (Costello, 2006). The setting a patient dies in also sets the context surrounding the death and the HCP's relationship to the patient who dies. For example, in a hospice the patient death is likely to be expected and the HCP will often have had time to form a relationship with the patient, as opposed to if the death is in a hospital emergency department where the death is likely to be unexpected, potentially not aligned with the 'natural order' such as paediatric death or death of young adults, and the HCP is unlikely to have had time to form a meaningful relationship with the patient. Previous research has suggested that the environment in which a patient dies may influence the role a HCP plays due to differences in coordination of care, teamwork and collaboration across different settings, namely hospices, hospitals and in the patient's home (Lawson, 2007). For these reasons, it may be inappropriate to compare reactions to patient deaths across hospital, hospice, care/nursing home and community settings.

Considering this rationale, the current review focusses on patient deaths which occurred in a hospital environment. This was also felt to be the environment in which it is most necessary to investigate reactions to patient deaths as 58% of deaths globally occur in an acute hospital setting (Broad et al., 2013). This decision is supported by previous research recommendations for example Cheung et al. (2018) concluded that further research is needed to explore self-competence in death work in individual healthcare settings, particularly HCPs working in hospitals. It may also

be inappropriate to compare reactions between hospital and hospice workers as previous studies have found that hospice nurses reported less fear of death and death avoidance attitudes compared to nurses working in emergency hospital environments (Bene & Foxall, 1991; Payne, Dean & Kalus, 1998) due to exposure and understanding of the dying process (Quinn-Lee, Olson-McBride & Unterberger, 2014). As per the assumptions detailed at the beginning of this thesis, another reason for this decision was that HCPs who have chosen to work in a hospice environment are likely to be more comfortable in dealing with death and dying.

### 3.6 Professional Roles

As this research focuses on traditional and non-traditional healthcare roles, namely doctors, nurses and EoL doulas, ideally this review would also include EoL doulas, however, as there was an existing systematic review (Rawlings et al., 2019) and inprogress scoping review (Yoong, Goh & Zhang, 2022) into all existing literature on EoL doulas at the time this review was conducted, both of which found no existing studies exploring how EoL doulas react to the death of a person they have been supporting, EoL doulas were not included in this review. That is, end of life doula was not included as a search term and no studies involving EoL doulas were returned via the search strategy for this review.

### 3.7 Reactions to and Coping with Patient Death

It is important to know how HCPs cope with the experience of patient death over time, particularly if there is long-term negative impact so that appropriate support can be identified and provided. How HCPs react to and cope with death events in the short-term has been linked to how they cope in the long-term; for example, Anderson et al. (2015) found that nurses who felt helpless and chaotic at the time of a patient's death were more likely to describe ongoing distress consistent with witnessing a traumatic event.

We know that this is particularly the case with HCPs' first and/or early experiences of patient death. In one of the landmark early studies into nurses' experiences with dying patients, Quint (1967) found that nurses' first experiences of patient death could influence their response to future patients' deaths over their nursing career. More recent research has further evidenced that these events are formative, with

early-career patient death influencing future coping strategies, attitudes towards caring for dying patients, clinical behaviours, physician burnout, career paths and professional decision making (Anderson, 2015; Gerow et al., 2010; Jackson et al., 2005; Powell & Toms 2014; Schulz-Quach, 2018; Whitehead, 2014).

Recent research such as that by Szczupakowska et al. (2021) concluded that there is a need for further research into how HCPs view and cope with patient death, and how this leads to them feeling prepared or unprepared to deal with this event again in the future – in other words, their death competency. Evidence suggests that nursing students feel unprepared to deal with patient death, feel inadequately supported to do so and tend to report intense emotional distress following a patient death (Rhodes-Kropf et al., 2005). Szczupakowska et al. (2021) highlighted the fact that even though many nursing students experience a patient death event often and early during their studies - 86.3% increasing to 99.3% in the second year of study - there exists an "exceedingly small amount of scientific research [which] concerns the response to patient death among nursing students" (p. 1). Though this may be true if we look at existing research relating to nurses only, by pulling together evidence from studies of HCPs more broadly we may be able to address the gaps and conflicting findings to reach a new understanding of responses and reactions to patient death.

### 3.8 Research Question

This review asks, 'what are the psychological influences on HCPs' initial reactions and coping responses to early career patient death events?'

### 3.1.1 Method

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidance (Moher et al., 2009) was adhered to throughout the process of this review. Registration of the review with Prospero was completed at the end of September 2020 (Prospero ID CRD42020204744).

## 3.1.2 Search Strategy and Selection Criteria

## 3.1.3 Search Terms

Piloting of search terms began with a relatively small number of search terms – namely patient death, HCPs, qualitative, and coping or response or reaction. However, after several trial searches it became clear that these terms did not have the specificity or sensitivity required as search results included many studies not relevant to the research question and studies which the researcher knew were relevant were not returned. It was therefore necessary to revisit and expand the search terms, specifically to unpack terms within 'qualitative', as per previous recommendations for high-quality qualitative literature reviewing (Barroso et al., 2003) and broaden the terms relating to patient death.

Finalised search terms were as follows, with Boolean operators "and" and "or" used to combine terms.

| Search Topic            | Search Terms  |
|-------------------------|---|
| Patient death           | patient death or patient dying or patient loss or     |
|                         | patient die*  |
| Qualitative             | (qualitative or thematic or IPA or interpretative     |
|                         | phenomenological analysis or grounded theory or       |
|                         | focus groups or diaries or diary or template or       |
|                         | discourse or conversation or observation or narrative |
|                         | or case or content)                                   |
| Response/coping         | (coping or appraisal or response or reaction or       |
|                         | emotion* or psychological)                            |
| Healthcare professional | (doctor* or physician* or nurse* or student)          |
| Early career            | (first or early)                                      |

Figure 1 Search Terms

The same search terms were used across all databases and the search was completed between September and October 2021, with a further search completed in July 2022 to check for any additional recent publications.

## 3.1.4 Search

A comprehensive search of the local University of Derby library system consisting of 227 databases was conducted along with Ethos and The Cochrane Library to check for any previous reviews on this topic.

The reference lists of included studies identified through this search process and of existing systematic reviews in this area were also screened for any studies which fitted the inclusion criteria of this review – no further studies were found.

## 3.1.5 Inclusion and exclusion criteria

The inclusion criteria restricted the review to studies conducted since 1990 through to November 2021, as research focusing on the topic of death, dying and HCPs began during this decade in response to the development of palliative care (World Health Organisation, 1990) and because research focusing on early-career experiences of nurses began in the late 1980s and did not extend to experiences of patient death until the 1990s (Zheng et al., 2016). Inclusion criteria required studies to be written in English, and the focus of the study must have been on the HCPs' *reaction* to a patient death. Studies had to explore HCPs' experiences of patient death at the time of the death and in the short time following the event. Studies could include early career HCPs and/or trainees as the focus of the review was on early career experiences of patient death.

Exclusion criteria included any studies conducted before 1990, studies which did not focus on the HCP's reaction to patient death for example those which explored experiences of stress or grief in a general sense, retrospective experiences of patient death looking back over a career, or studies which focused on the experience of providing care to dying patients were excluded. Studies which were not conducted in a hospital setting were also excluded.

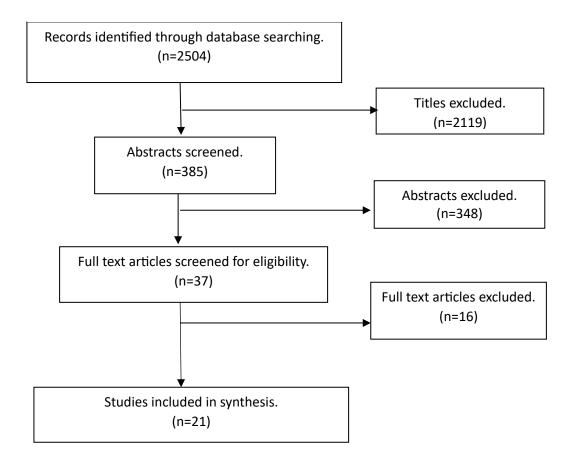
Conference extracts and letters, posters, magazines, and news items from nonacademic sources were excluded. Papers which did not include qualitative data were also excluded, along with textbooks, and articles and editorials unless they contained original empirical data. Papers from peer reviewed journals, unpublished reports and doctoral dissertations/theses were included to avoid any file drawer issues. Table 1 Inclusion and exclusion criteria

| Inclusion Criteria                         | Exclusion Criteria                    |
|--|---------------------------------------|
| English language                           | Non-English language                  |
| Published since 1990                       | Published before 1990                 |
| Study conducted in a hospital setting      | Not in a hospital setting             |
| Qualitative data present                   | No qualitative data present           |
| Qualitative or mixed methods study         | Quantitative study methodology        |
| methodology                                | Study focus is not on early career    |
| Study focus is on early career experiences | experiences of patient death          |
| of patient death                           | Magazine articles/conference extracts |
| Peer reviewed journal/unpublished          | and letters/posters/news items from   |
| reports/theses/dissertations               | non-academic sources                  |

### 3.1.6 Study Selection

The search strategy, presented in the PRISMA flow diagram below, yielded 2,504 articles after using the database search function and Microsoft Excel software to find and exclude duplicates. The 2,504 articles were reviewed by title by EC and AB, and of these 385 articles were included for review of abstracts to identify studies which appeared to fit the inclusion criteria (inter-rater reliability off 93%). Abstract review resulted in 348 being excluded due to duplicate (n=45), article or editorial (n=16), study focus on dying not death (n=59), study focus on broad experiences of providing palliative care not death (n=75), non-hospital environment (n=5), book chapters (n=7), study focus on general death attitudes (n=28), quantitative study (n=11), individual case study article (n=2), reviews of training programmes (n=4), reviewing a scale (n=4) and report of a memorial service (n=1).

#### Figure 2 Prisma Flow Diagram



Full texts of the remaining 37 studies were sought via the following: open access (n=33), inter-library loan (n=3) and direct request to author (n=1). 9 studies were excluded through the full text review process for the following reasons: quantitative study with no qualitative data (n=1); participants did not work within a hospital setting (n=3); meta-synthesis (n=1); did not focus on response to patient death (n=3), plagiarism of another study included in review so therefore judged to be unreliable (n=1). Where articles had used a mixed methods approach, only the qualitative section of the results was extracted. In one paper the setting in which the study was conducted was unclear ("clinical setting") so the researcher contacted the study authors to request clarity on this however no response was received so the study was excluded. The reference lists of papers which met the inclusion criteria were scrutinised for further studies not identified via the electronic search.

Articles retained following full text review originated from the following databases: CINAHL Complete (n=9), Pubmed (n=4), DOAJ Database of Online Journals (n=2), Research Gate (n=2), Wiley Online Library (n=1), Medline (n=1), JSTOR Life Sciences Collection (n=1), Wiley Jisc Collections and Publish Open Access (n=1).

## 3.2 Data Extraction

A total of 21 studies representing 601 participants were included. Data was extracted using a standardised 23 item data extraction sheet (Appendix G) by the primary reviewer (EC) with 50% of the data being extracted by a second reviewer (AB) independently for quality assessment purposes to minimise bias. First order data - of 'raw' qualitative data in the form of quotes reported in the study, and second order data – the analytical commentary of the papers' authors, as well as details of the study design, research question, method, participant characteristics and findings. The data extraction form was piloted with an initial 8 studies and minor improvements were made to support the data extraction process. Both reviewers then met to discuss extraction. Inclusion/exclusion decisions were predominantly consistent, however where differences in decisions occurred these were resolved through discussion until agreement reached, a third reviewer was available should a third opinion have been required.

# 3.3 Quality Assessment

In the context of a systematic review the term quality refers to "the degree to which a study employs measures to minimize bias and error in its design, conduct and analysis" (Khan et al., 2003, p. 39). There and advantages and disadvantages to conducting quality assessment at different stages of the review process. For this study quality assessment was conducted after study data was extracted, so that data extraction was less likely to be biased by the researcher's knowledge of the study quality; however, this meant there was a chance that poor-quality studies were included prior to data extraction.

The Critical Appraisal Skills Programme (CASP) checklist was used to assess the quality of studies included in the review. The CASP checklist is the most used quality assessment tool in qualitative synthesis and is recommended by the Cochrane Qualitative and Implementation Methods Group (Noyes et al., 2018). It is also recommended for those who are new to the process of assessing quality in qualitative research, and therefore suitable for use by early career researchers

(Long, French & Brooks, 2020). The checklist was developed for use in healthrelated research making it a 'good fit' for this research topic (Long, French & Brooks, 2020). The CASP checklist consists of 10 items which each relate to a different part of qualitative study methodology (see Table 4 below).

Despite its wide use, the CASP in its original form is not without criticism. For example, the current CASP checklist does not facilitate the assessment of a study's qualitative paradigm in terms of its clarity and appropriateness to the study's aims resulting in recent modifications to the CASP tool by including items on research paradigm (Long, French & Brooks, 2020). This revision of the CASP was published during this review and the researcher therefore moved to using the up-to-date version, meaning that the additional question '*are the study's theoretical underpinnings (e.g., ontological and epistemological assumptions; guiding theoretical framework (s)) clear, consistent and conceptually coherent?*' was also included.

Though there is little academic consensus regarding core criteria for the CASP (Long, French & Brooks, 2020), in line with Cochrane advice against scoring studies when undertaking quality assessment (Noyes et al., 2018) this review organised studies into one of three quality assessment categories - CASP criteria totally met, partially met, or not met. This method of categorising studies was chosen as it has been used in other systematic reviews and meta-syntheses in the field of health and social care (Billings et al., 2021) based on methods originally described by Lachel et al. (2017). Using item 7 (have ethical issues been taken into consideration?) as an example to explain the process of classifying studies, a study which was judged to have totally met the CASP criteria would provide a narrative evidencing that ethical issues were identified and addressed; a study judged as having partially met the CASP criteria may say that the study was granted ethical approval but gave no further details; a study not meeting the CASP criteria would not mention ethical issues. It is important to acknowledge that in the case of studies not meeting the criteria this does not mean that the researchers did not consider these issues, but that there is no evidence of this in the available report of the study.

 Table 2 Quality of Included Studies: Number of Studies Meeting CASP Criteria

|  | Totally | Partially | Not |
|--|---------|-----------|-----|
|  | met     | met       | met |
| 1. Was there a clear statement of the aims   | 17      | 2         | 2   |
| of the research?                             |         |           |     |
| 2. Is a qualitative method appropriate?      | 21      | 0         | 0   |
| 3. Was the research design appropriate to    | 17      | 3         | 1   |
| address the aims of the research?            |         |           |     |
| 4. Are the study's theoretical underpinnings | 1       | 1         | 19  |
| (e.g., ontological and epistemological       |         |           |     |
| assumptions; guiding theoretical             |         |           |     |
| frameworks(s)) clear, consistent and         |         |           |     |
| conceptually coherent?                       |         |           |     |
| 5. Was the recruitment strategy appropriate  | 16      | 4         | 1   |
| to the aims of the research?                 |         |           |     |
| 6. Were the data collected in a way that     | 15      | 6         | 0   |
| addressed the research issue?                |         |           |     |
| 7. Has the relationship between researcher   | 5       | 1         | 15  |
| and participants been adequately             |         |           |     |
| considered?                                  |         |           |     |
| 8. Have ethical issues been taken into       | 5       | 5         | 11  |
| consideration?                               |         |           |     |
| 9. Was the data analysis sufficiently        | 9       | 5         | 7   |
| rigorous?                                    |         |           |     |
| 10. Is there a clear statement of findings?  | 10      | 8         | 3   |
| 11. How valuable is the research?            | 8       | 10        | 3   |

# 3.3.1 Quality Assessment Results

Included studies fell into all three categories of quality assessment – low (k=6, medium (k=8) and high (k=7) quality. Whilst most studies did include a clear statement of aims, a number of these did not use a research design which enabled

the research aim to be fully addressed (Granek et al., 2015, Gul et al., 2020; Heise & Gilpin, 2016), for example stated aim as investigating reaction to patient death but then asked the participants questions about their experience of providing end of life care. Only two studies (Sharma, 2017; Trivate et al., 2019) included reporting of ontological and epistemological underpinnings. Of the six studies which were judged to be of low quality, two contained very little qualitative data and no new themes were generated from this, four lacked details in reporting of ethical considerations, recruitment, analysis and did not present a clear statement of findings.

### 3.4 Meta-synthesis method

Meta-synthesis refers to the amalgamation of qualitative data from across a body of studies with the aim of explaining the findings of the group of studies as a whole in relation to a specified research aim or question. It is an iterative process, which goes beyond simply merging data from separate studies by creating a new data set to enable interpretation and the broadening of understanding regarding a particular phenomenon (Grant & Booth, 2009). Meta-synthesis was an appropriate analytic technique as the aim was to generate new theoretical insight into how HCPs respond to and cope with patient death, and meta-synthesis has been used across a wide range of health-related research areas (Walsh & Downe, 2005).

The term qualitative meta-synthesis was first coined by Stern & Harris (1985), and since this time there has been ongoing debate about the scope of meta-synthesis – whether it should utilise a narrow, precise approach based on the research question or whether it should opt for a broader stance (Walsh & Downe, 2005). This debate has in part been caused by attempts to view meta-synthesis techniques as similar to meta-analysis techniques – that there should be a fully-formed strategy prior to the search beginning and that the process should be linear. Barroso et al. (2003) argued that such a strategy is not reflective of real life and that instead the focus should be on transparent reporting – that the process can follow a more divergent, evolving path so long as this is clearly stated (Walsh & Downe, 2005). In this PhD, the researcher's stance is aligned with the latter of these viewpoints, particularly since the literature review focuses on an emerging research area and so it was not possible to predict ahead of time the direction this would take and there was value in allowing this to be an open process.

A line of argument synthesis technique was used as data related to different aspects of the research question and synthesis involved drawing these together to facilitate new interpretation of the data. First order data (direct quotes from participants) and second order data (analytic commentary from each included study were entered into NVivo, which was used to organise and analyse data. Node creation and coding functions were used to create third order data, i.e., to identify new themes through thematic analysis, a systematic qualitative analysis method allowing detailed description of themes within data and along with interpretation of the wider topic (Boyatzis, 1998; Braun & Clarke, 2006).

### 3.5 Results

### 3.5.1 Characteristics of Included Studies

Key characteristics of included studies are summarised in Table 5.

Included studies were from academic journals (n=20) along with one unpublished thesis (Sharma, 2017). Included studies were carried out between 2000 and 2019, with publication years ranging from 2003 to 2021. Study population was international and was made up of HCPs from the USA (k=6, n=126), Canada (k=4, n=61), Mexico (k=1, n=7), New Zealand (k=1, n=17), Spain (k=1, n=12), Sweden (k=1, n=17), Ireland (k=1, n=28), Turkey (k=1, n=105), Wales (k=1, n=5), Taiwan (k=1, n=12) and Lebanon (k=1, n=16).

Study aims followed a general theme of exploring HCPs experience of patient death including their experience of the death event itself and subsequent coping/emotional reaction/needs. It was notable that definitions of 'reaction to patient death' were often not provided or were broad, with 'patient death' sometimes including pre-death tasks such as breaking bad news (Alvarez-del-Rio et al., 2013). 18 studies specifically focused on reaction to patient death, 3 studies had a wider scope but included reaction to patient death so still qualified for inclusion in the review.

In terms of data collection methods, most studies used semi-structured interviews (k=14, n=359), followed by focus groups (k=7, n=130), free text from open text response survey (k=3, n=73), mixed methods survey with open text response boxes

(k=2, n=61), a combination of interview and focus group (k=1, n=29), and a narrative questionnaire for narrative enquiry (k=1, n=12).

Analytic techniques varied across included studies. Most frequently used was thematic analysis (k=6, n=165), followed by grounded theory (k=5, n=110), content analysis (k=3, n=77), interpretative phenomenological analysis (k=2, n=31), Colaizzi seven step (k=2, n=24), meaning categorisation (k=1, n=7), a combination of thematic analysis and interpretative description (k=1, n=5), a combination of grounded theory and an anthropological mode of interpretive analysis (k=1, n=163).

| Author<br>Álvarez-del-Río, Ortega-<br>García, Oñate-Ocaña, &<br>Vargas-Huicochea, 2013 | <b>Study Design</b><br>A semi-structured, focussed, or<br>centered interview was used.   | Analytic Strategy<br>Meaning categorization  |
|--|--|--|
| Anderson, Kent, & Owens, 2015  | Individual, semi-structured, face to face interviews.  | Thematic analysis to identify<br>emerging themes.<br>Interpretative<br>Phenomenological Analysis to<br>understand participants'<br>experiences |
| Batley, et al., 2017   | Semi-structured qualitative interviews   | Thematic content analysis  |
| Edo-Gual, 2014   | Qualitative descriptive and<br>hermeneutic study utilising<br>semi-structured interviews   | Colaizzi's seven step data<br>analysis   |
| Ffrench-O'Carroll, Feeley,<br>Crowe, & Doherty, 2019                                   | Cross-sectional, observation<br>study utilising quantitative and<br>qualitative methods.<br>Questionnaires and interviews<br>were used. Texas Revised<br>Inventory of Grief was used to<br>assess grief severity.<br>Shortened Impact of Event<br>scale was used to assess<br>emotional impact. Brief COPE<br>tool was used to assess coping<br>strategies | Qualitative data were analysed<br>using conventional content<br>analysis.  |
| Gerow, et al., 2010  | In-depth, semi-structured interviews   | Van Manen's (1990)<br>interpretative<br>phenomenological analysis<br>(IPA)   |
| Good, et al., 2004   | Semi-structured interviews   | Initial thematic analysis, coding using ATLAS. Grounded theory   |

Table 3 Study Characteristics

|  |   | and an anthropological mode of interpretive analysis  |
|--|---|---|
| Granek, Bartels, Barrera, & Scheinemann, 2015                  | Semi-structured interviews  | Grounded theory method for<br>data collection and analysis.<br>NVivo was used to organise,<br>code and store data |
| Granek, Bartels,<br>Scheinemann, Labrecque, &<br>Barrera, 2015 | Semi-structured interviews  | Grounded theory method  |
| Gul, et al., 2020  | Focus group interviews.   | Thematic analysis   |
| Heise & Gilpin, 2016   | Descriptive mixed methods. An<br>online survey utilising both<br>qualitative and quantitative<br>questions.   | Content analysis  |
| Huang, Chang, Sun, & Ma, 2009                                  | One on one, in-depth, semi-<br>structured interviews.   | Colaizzi's seven step data analysis   |
| Kelly & Nisker, 2010   | Telephone interviews and focus groups   | Grounded theory   |
| Mast & Gillum, 2018  | Qualitative case study.   | Thematic analysis   |
| Parry, 2011  | A phenomenological approach using focus groups.   | Thematic analysis   |
| Powell & Toms, 2014  | Qualitative research design using focus groups.   | Thematic analysis   |
| Ratanawongsa, Teherani, & Hauer, 2005                          | One on one, in-depth, semi-<br>structured interviews.   | Grounded theory   |
| Rhodes-Kropf, et al., 2005                                     | Mixed methods. Qualitative<br>data collected through one-to-<br>one, semi-structured interviews<br>and quantitative data collected<br>through questionnaires. | Grounded theory   |
| Sharma, 2017   | One-to-one interviews   | Thematic analysis   |
| Thompson, Austin, & Profetto-<br>McGrath, 2010                 | One-to-one interviews   | Interpretive description  |
| Trivate, Dennis, Sholl, &<br>Wilkinson, 2019                   | Narrative enquiry using narrative questionnaires.   | Thematic analysis   |

# 3.5.2 Participant Characteristics

A summary of participant characteristics is presented below in Table 6. Across 21 included studies a total of 601 participants are represented, all of whom were

working in a hospital setting. Such settings ranged from acute medical wards to accident and emergency departments to long-term care and palliative wards. As a result, the nature of patient deaths experienced also varied, with HCPs working in accident and emergency departments more likely to experience sudden and unexpected patient death and those in palliative care wards more likely to be describing an experience associated with an expected patient death. In terms of experience, some participants were in training: student nurses (n=167), medical students (n=274) and physiotherapy students (n=15) and others were fully qualified: qualified nurses (n=49) and qualified doctors (n=74), therefore most data related to patient death experiences of trainees, which was to be expected as the review focus was on early-career experience. 15 studies provided data regarding the age of participants, 6 did not supply data regarding age. From those that did report, age of participants ranged from 18-74 years. There were more female participants (n=317) than male (*n*=175) across 12 studies that reported gender. Only four studies reported information regarding the ethnicity of participants representing 117 participants, which described participants as Caucasian (n=32), white (n=36), New Zealand European (n=11), Asian-American (n=8), Asian (n=7), other European (n=4), African-American (*n*=3), Black (*n*=3), New Zealand Māori (*n*=2), Latino (*n*=1), Hispanic (*n*=1) and other (n=9).

| Authors  | Participant<br>characteristics   | Age                               | Gender             |
|--|--|-----------------------------------|--------------------|
| Álvarez-del-Río,<br>Ortega-García, Oñate-<br>Ocaña, & Vargas-<br>Huicochea, 2013 | 7 oncology residents   | Not supplied                      | Not supplied       |
| Anderson, Kent, &<br>Owens, 2015   | 20 registered nurses.<br>Ethnicity NZ European<br>11, Other European 4,<br>NZ Maori 2, Other 3 | Age 21-30 8, 31-40 9,<br>41-50 3. | 3 male, 17 female  |
| Batley, et al., 2017   | 16 medical students  | Mean age 23.7.                    | 10 female, 6 male  |
| Edo-Gual, 2014   | 12 nursing students  | 19-37                             | 11 female, 1 male  |
| Ffrench-O'Carroll,<br>Feeley, Crowe, &<br>Doherty, 2019                          | 28 doctors   | 29-34                             | 15 male, 13 female |
| Gerow, et al., 2010  | 11 nurses who had experienced the death  | Not supplied                      | Not supplied       |

#### Table 4 Participant Characteristics

|   | of a patient whom they had cared for  |                                    |                    |
|---|---|------------------------------------|--------------------|
| Good, et al., 2004  | 163 Internal medicine students  | 28-94.                             | 51% male           |
| Granek, Bartels,<br>Barrera, &<br>Scheinemann, 2015               | 6 paediatric oncology<br>fellows  | Not supplied                       | 3 male, 3 female   |
| Granek, Bartels,<br>Scheinemann,<br>Labrecque, & Barrera,<br>2015 | 21 oncologists Varied<br>in sub-specialities and<br>ethnicities, specific<br>numbers not provided             | 31-74.                             | 10 male, 11 female |
| Gul, et al., 2020   | 105 nursing students,   | Not supplied                       | 91 female, 14 male |
| Heise & Gilpin, 2016  | 33 nursing students.<br>Ethnicity - 32<br>Caucasian, 1 'other'  | Age 18-20 11, 21-23<br>16, 24-29 6 | 29 female, 4 male  |
| Huang, Chang, Sun, &<br>Ma, 2009                                  | 12 student nurses,  | 19-21.                             | All female         |
| Kelly & Nisker, 2010  | 29 final year medical students  | Not supplied                       | Not supplied       |
| Mast & Gillum, 2018   | 16 community hospital nurses  | 26-64                              | Not supplied       |
| Parry, 2011   | 5 undergraduate<br>nursing students   | 21-44.                             | Not supplied       |
| Powell & Toms, 2014   | 15 Physiotherapy students   | 21-31.                             | Not supplied       |
| Ratanawongsa,<br>Teherani, & Hauer,<br>2005                       | 28 medical students<br>Ethnicity - 13 white, 8<br>Asian-American, 3<br>African-American, 1<br>Latino, 3 Other | 22- 36                             | 14 male, 14 female |
| Rhodes-Kropf, et al., 2005  | 26 third year medical<br>students Ethnicity - 23<br>White, 7 Asian, 3<br>Black,1 Hispanic, 2<br>Other         | Average age 26.                    | 14 male, 22 female |
| Sharma, 2017  | 12 residents and early career physicians  | 27-36                              | Not supplied       |
| Thompson, Austin, &<br>Profetto-McGrath,<br>2010                  | 5 surgical nurses   | Not supplied                       | Not supplied       |
| Trivate, Dennis, Sholl, & Wilkinson, 2019                         | 12 medical students   | Age 20-24 9, 25-29 2,<br>30-34 1.  | 8 male, 4 female   |

### 3.5.3 Study findings

This review asked the question "What are the psychological influences on HCPs' initial reactions and coping responses to early career patient death events?". The process of answering this question is split into three parts. Firstly, this review will present the frequency at which themes are evident in all included studies to give an overall picture of the systematic review findings. Secondly, results of the meta-synthesis will be presented in the form of key psychological factors related to response to and coping with patient death events noted throughout the studies included in this review. Thirdly, environmental factors will be discussed as the knock-on effect of these on psychological factors were too prominent to overlook and are necessary to ensure the real-world application of this study's findings.

## 3.5.4 Second order themes summary: initial reactions to patient death

Initial reactions to patient death events covered a wide range of emotions (most frequently self-blame, shock, numbness, and fear), behaviours (such as leaving the room) and physical reactions (shaking, feeling nauseous).

| Theme   | Frequency |
|---|-----------|
| Self-blame/guilt                                      | 18        |
| Shock/disbelief                                       | 10        |
| Physical reactions                                    | 12        |
| Fear  | 9         |
| Numbness  | 8         |
| Removing self from situation (e.g., leaving the room) | 5         |
| Anger or frustration                                  | 4         |
| Relief  | 2         |

Table 5 Identified Initial Reactions to Patient Death

### 3.5.5 Second order themes summary: coping strategies

Coping strategies could broadly be grouped into reaching out or 'going into' oneself, in line with engagement vs disengagement coping strategy categorisation (Carver and Connor-Smith, 2010). Participants reported that they coped by speaking to others or, in contrast, by 'bottling up' their emotions and avoiding talking about how they felt. The most frequently identified coping strategies present in studies included in this literature review are presented in Table 8 below along with a frequency number showing how many times this theme was identified within the data.

| Table 6 Ident | tified Coping | Strategies |
|---------------|---------------|------------|
|---------------|---------------|------------|

| Theme                                 | Frequency<br>within data |
|---------------------------------------|--------------------------|
| Seeking social support                | 83                       |
| Detachment/Distancing                 | 33                       |
| Avoidance                             | 29                       |
| Positive reframing                    | 27                       |
| Existential reflection (including     | 25                       |
| religion/spirituality/meaning making) |                          |
| Distraction and keeping busy          | 24                       |
| Time alone to reflect                 | 19                       |
| Post-mortem rituals                   | 15                       |

### 3.6 Meta Synthesis

### 3.6.1 Summary of identified psychological factors

Before discussing the meta-synthesis findings in detail, it is helpful to summarise the main psychological factors affecting initial reactions to patient death and subsequent

coping, which were identified through the review process, and which formed the four themes presented in the following section of this chapter.

 Table 7 Identified Psychological factors

| Psychological Factors                          | Summary  |
|--|--|
| Relation to past bereavement experience and/or | Participants previous experiences of   |
| personal relation to the patient               | relatives or friends dying influences how<br>they reacted to and felt about some<br>patient deaths, particularly when the<br>patient reminded them of their relative. If<br>the patient's situation reminded the HCP<br>of themselves for example if they were<br>the same age or if the patient was a<br>parent of a child the same age as their<br>own, this could make the patient death<br>more difficult to deal with and resulted in<br>thoughts of "that could have been me"<br>which could cause additional distress<br>and fear.  |
| Emotional expression                           | <ul> <li>There were a wide range of participants</li> <li>attitudes as to whether they could and</li> <li>should express their emotions following a</li> <li>patient death. Participants looked to role</li> <li>models around them for cues on whether</li> <li>they could safely express emotion,</li> <li>whether this would be viewed as</li> <li>unprofessional and whether they could</li> <li>pause and reflect after a patient death or</li> <li>was there pressure to keep busy and</li> <li>move on to the next patient. They</li> <li>described taking on these views</li> <li>themselves, demonstrating that such role</li> <li>models had a lasting effect on their</li> <li>emotional expression.</li> </ul> |
| HCP's individual appraisal of the death event  | If the HCP viewed the death as a failure<br>on the part of themselves or the wider   |

### Use of engagement coping

system, they were more likely to describe feelings of self-blame and guilt, ongoing distressing thoughts of "If only I had..." and a need for reassurance from others. Alternatively, if the HCP viewed the death as an opportunity for them to learn, develop in their career, gain experience, and grow personally, this appeared to negate some of the potential negative impact of the death event and allowed the HCP to reframe the event in a positive light. This is linked to the concept of challenge in appraisal theory, one of the three key psychological aspects of 'psychological hardiness' or resilience (Kobasa, 1979, 1982). Those who sought support from others and received validation experienced a 'positive snowball' effect in that they felt they weren't alone in experiencing their emotional reaction and then in turn felt more able to reach out and show emotions and share their feelings in the future. Participants who had, and utilised, debriefing opportunities to talk about the patient death event itself, their feelings following this, to ask questions and to gain understanding into what they witnessed and correct misconceptions about the physical dying process described feeling more positive following the patient death event and more confident that they would be supported in future.

Based on these findings, the results of this meta-synthesis, which included 21 studies and addresses the question '*what are the psychological influences on HCPs' initial reactions and coping responses to early career patient death events?*', can be summarised in terms of four key themes: individual appraisal, use of engagement coping, emotional expression and past bereavement experiences and relatedness to patient.

Table 8 Psychological Influences: Themes and Subthemes

### **Themes and Subthemes**

- 1. Individual Appraisal
  - 1.1 Death as failure
  - 1.2 Challenge (death event as learning opportunity)

### 2. Use of Engagement Coping

- 2.1 Peer validation
- 2.2 Debriefing
- 3. Emotional Expression
  - 3.1 Professionalism
  - 3.2 Role-models
  - 3.3 Keeping busy

### 4. Past bereavement experiences and relatedness to patient

### 3.6.2 Themes

### 3.6.3 Theme 1: Individual Appraisal

Subthemes: patient death as failure, patient death as opportunity

It was evident throughout the data that HCPs could be present at similar death events but react differently, and that this was due to individual differences in how they made sense of what they had witnessed and the narrative they formed around this. This theme 'individual appraisal' refers to this and covers the subthemes of viewing 'patient death as failure' and 'patient death opportunity'.

HCPs' individual appraisals of a patient death event for example whether they viewed the death as a personal or collective failure, was a recurring theme. Others

viewed the death as a personal learning opportunity or a 'rite of passage' which tended to lead to more positive descriptions of the experience, demonstrating that how the individual framed this event - leading up to it in their expectations, during the event viewing their role (as a learner) and afterwards – played a key part in determining their reaction to the death.

### Subtheme 1: Death as Failure

A number of participants described both personal feelings that a patient dying constituted a failure on their part and/or on the part of the service, and wider attitudes across their colleagues that this was the case.

*"I think and there was still a sense that palliative meant maybe a failure...that you failed to cure".* 

Some participants talked about using coping strategies such as social support and group debriefing to counter the feeling of personal failure following a patient death.

"This sense that you've failed can be very strong, and that's often why we end up having these group discussions to almost just reassure ourselves, there was no personal failure".

This feeling of personal failure had knock-on negative effects, for example it could prevent the HCP from receiving thanks from the patient's family and turned what could have been positive feedback into additional feelings of guilt.

"Feeling like a failure was also described frequently as a response to patient death. A sense of failure was particularly salient when patients relapsed and the oncologist understood that cure would be unlikely. Some oncologists described feelings of failure particularly intensely when families thanked them after the patient's death. Some noted that the gratitude felt undeserved since they were not able to cure the patient, and therefore, they felt they had failed the family and the child".

A number of participants felt that this message originated from their senior colleagues, describing 'death is a failure' of one of the main messages they received throughout their training.

"Students spoke of the messages they learned about emotions and death from residents and attending physicians during their third-year rotations. The two main messages were....and death is a failure".

We know that death is often viewed as a failure in medical cultures, both explicitly though language such as 'failure to rescue' documentation (used to refer to paperwork which is completed after a patient's death) and more pervasively through medical curricula (Branch et al., 1998; Field & Cassel, 1997; Kelly & Nisker, 2010). It is therefore not surprising that many participants described their experience of patient death using this language. This was linked to the fact that, as one study put it, *"living was viewed as a medical goal in and of itself"* (Rhodes-Kropf et al., 2005, p.638). Such a goal is entirely appropriate in emergency medicine settings where the goal is to save the person's life through quick action and decision making, however it is important to remember that many participants in this study were working in palliative care settings in which this goal is less fitting and is likely to be unhelpful for the HCPs working in these settings as it is an unachievable goal. It is not difficult to imagine that in these settings, HCPs may be more likely to react to a patient death by feeling that they were at fault, as 'failure' implies that something could have been done to make the situation a 'success'.

### Subtheme 2: Patient Death as Opportunity

A second subtheme, 'patient death as opportunity', was evident in the data, as many participants described how a patient death provided them with a positive opportunity for learning and personal growth.

Participants frequently identified learning opportunities provided by their death experience and regarded it as a hurdle or even a rite of passage as a nurse.

"Oncologists also noted that patient deaths gave them a new perspective on life that included appreciation for the mortality and health of themselves and their families, a sense of humbleness about their work, and a greater desire to live in the moment and more fully because of the precariousness and fragility of life. In this sense, oncologists described a process of personal growth as a result of patient deaths". "I think each patient's death is an experience that may help you think about practical bits and non-practical bits that may help you do better next time".

"So I was just, I don't know, practicing CPR. That's it. I wasn't feeling anything. I wasn't affected by the death... I was just learning something new".

These examples involve the HCP modifying their way of thinking about the patient death event and their role in this situation to result in a positive appraisal which is likely to facilitate positive emotions and learning. This process of viewing a difficult situation as a positive learning opportunity is known within appraisal theory as 'challenge', which along with commitment and control, is one of the three key psychological aspects of 'psychological hardiness' or resilience (Kobasa, 1979, 1982). Previous research suggests that participants in this study who reframed their experience of patient death into an opportunity for growth and learning would be less likely to view the patient death event as a threat to their wellbeing (Skinner and Brewer, 2002).

### 3.6.4 Theme 2: Use of Engagement Coping

### Subthemes: peer validation, debriefing

In line with previous research which concluded that the most useful distinction in coping strategies is engagement vs. disengagement (Carver and Connor-Smith, 2010), the theme 'engagement coping' was used to draw together the psychological factors and coping responses to patient death that were most common across the data. Engagement coping refers to coping strategies which involve 'turning towards' the event and associated emotions and taking direct action such as seeking support (Carver and Connor-Smith, 2010). This theme encompasses two subthemes – peer validation and debriefing.

### Subtheme 1: Peer Validation

Participants in all included studies spoke of turning to others following experiencing a patient death, primarily for emotional support and seeking someone to normalise how they were feeling:

"[The team members] talked about [the death] to me individually . . . it showed me that they were genuinely concerned . . . they expressed their own feelings about it too . . . it's not like them saying, "Well, you've got to deal with this because you're new".... "It's still kind of hard for all of us."

"I really would have liked to ask someone you know, "Isn't this awful?" You know kind of see if they felt the same way I did, rather than wondering, OK, does it feel this awful every time? Is it just because I'm a third year and this isn't what I'm accustomed to every day? I would definitely— especially on haematology oncology— have liked to ask the attendings how they cope with this".

"The rest of the day was really weird. It was very surreal. I remember it was right before lunch and the other student and I didn't eat lunch. . . . It was good to have her there because the two of us talked about it [the patient's death] afterwards and just felt that was the craziest thing we have ever seen. . . . We hadn't been around any death at all".

The use of seeking social support as a coping strategy was not sufficient to guarantee effective coping alone, the key factor appeared to be whether the HCPs emotions and difficulties were validated when they did or whether they felt dismissed or alienated as a result:

"Everyone . . . was just busy doing their regular things . . . then I remember seeing my classmate and seeing that she had been crying and I grabbed onto her and said, "I think you feel the same way that I do, can we go into this room and talk, because I can't handle this." And she said "Oh thank God, everyone else just seems to be going along on their way and it just seems that it is just us that are upset by this".

"The only thing I ever heard from anyone was, "Such an interesting case, if you don't love this, you don't love medicine".

"It's quite nice knowing that other people are going through the same thing; that helps".

This subtheme highlights the role of external factors in effective coping as previous research suggests that engagement coping is more likely to result in positive

outcomes than disengagement coping (Carver and Connor-Smith, 2010), however in these examples we see how such positive outcomes rely on the individual receiving a positive response to them seeking social support and validation.

### Subtheme 2: Debriefing

A second subtheme within engagement coping was debriefing, which is closely linked to peer validation in that it involves eliciting support from others. However, debriefing provides a more formalised support system, providing a space for HCPs reactions and emotions following a patient death to be validated. Several participants spoke of how useful debriefing was both to their wellbeing and learning:

"Debriefing after the death has always been a good thing. Everybody talks openly, it's nobody's fault. It's – 'these things happen'. Those kind-of talks afterwards, I've always found to be a good thing".

The format of available debriefing opportunities varied across participants. In some cases, debriefing was built into the structure of the department for example if the deceased patient was still included in ward rounds, providing dedicated time for the HCP to speak about the patient's end of life care and death. This was sometimes accompanied by an additional routine which brought comfort - one participant described folding up the patient's chart as part of a post-death ritual:

"Rounding on somebody who died . . . helps bring closure to taking care of that person, instead of just dropping them off the list like somebody who had been discharged, we just fold up the card and let them go".

It was common for participants to describe how they were left with lingering questions about their involvement in the patient death which caused them distress, and how a debriefing opportunity would have allowed them to answer these questions, thereby reducing ongoing distress:

"I wondered could this have been prevented?.. is this my fault? Should I have done more? What should I have done differently? Um, you know, how, how could we have done this differently to have avoided this outcome? Um, and for a while—you know, I—I understood it wasn't my fault. I knew that at my level of training, this outcome was not my fault but I couldn't help feeling that it was. You know, and logically knowing that it wasn't and feeling that it was, you know, both of these... I felt guilty. I don't know that I had a reason to be guilty, but I felt guilty".

"Had I not convinced him the morphine was the right thing ... would he have lived longer? That's part of the blame".

"one of the first things that comes to mind is "did I do something wrong?" And so there's an immediate um, one of the immediate reactions is "uh-oh, did I make a mistake here?" "Did we do the wrong approach? Did we miss something? Did we, think of doing something? Did I not do the right set of scans?"

Despite the known benefits of debriefing (Heise & Gilpin, 2016; Tanner, 2006), most instances of debriefing mentioned in the data were related to participants expressing a want and/or need for more, or any, debriefing opportunities:

"I think it would have been nice to have been prepared beforehand for such experiences by telling students that they should debrief with their instructor and it's okay if this is a big deal".

"Debriefing sessions at the end of the month . . . or maybe, you know, within a few days of the patient's death. Those would be useful . . . you could at least vent out your feelings and your guilt, and your sadness, and you'd find out that everyone shares those feeling and you wouldn't feel isolated".

"Debriefing sessions with students were rare, and many students felt inadequately supported. Thus, a unique opportunity to teach about death, emotions and coping with stress is often lost".

This subtheme demonstrates the need and demand for debriefing opportunities from HCPs themselves and suggests that such support is not as readily available as is required to facilitate HCPs' wellbeing and learning.

### 3.6.5 Theme 3: Emotional Expression

Subthemes: Role-models, keeping busy

Whilst expressing emotion is also considered to be an engagement coping strategy as it involves an effort to share feelings outwardly and elicit response from others (Carver and Connor-Smith, 2010), this theme was so pervasive throughout the data in this review that emotional expression warrants its own theme. Showing or hiding emotion following being present at a patient death was the most frequently occurring theme in this meta-synthesis – it was present in all included studies. In this study, participants almost always experienced strong emotional reactions to their early-career experience of patient death, however whether they allowed themselves to display this, or 'bottled up' the emotion varied greatly between participants.

### Subtheme 1: Professionalism

There was a distinct split between participants who felt able to show emotion and held positive beliefs about doing so - that this can be helpful for themselves, can show patients and family members that they care and can enable them to elicit and receive support from their peers.

"Mary and one of the other nurses pulled me aside and said it was OK to cry with the family ... it lets the family know that someone cared about their loved one when they couldn't be there to take care of them. That made a big difference that it's OK to be emotional".

Others spoke of "running away to cry" or "holding in" their emotions until they were alone as they felt that it would be unprofessional:

"I was not sure what to do with the emotion...you feel that you can't express it to them [qualified staff] and I think that just makes it worse".

"I found that very, very difficult to not show any sort of feelings at all because, I thought, you know, that's not professional".

"Began to emotionally distance myself from the family and their needs. I pretended I could not feel their sorrow; however, every time I saw my patient I cried inside".

"Usually try to find a somewhat non-public place to do it. So that all the nurses on the ward aren't saying 'look he lost it". One participant articulated how they felt conflicted about whether to show emotion or not, particularly in front of patients:

"I can see that when they're in the palliative course and at the end of life, it may be more appropriate to show those emotions [of sadness, crying etc.]. I find that the patient needs someone, not only who's commiserating with them at the end of life, but someone who is strong and supportive at the end of life. I'm still conflicted with completely expressing myself at the time of death because the patient... does the patient want me to support them and be strong? Or does the patient want me . . . to really express my feelings and just say how sad I feel and maybe even cry if I get to that stage?".

Sometimes participants attempted to avoid feeling and showing emotion as they feared this would inhibit their ability to work effectively. The following examples provide evidence of 'emotional dissonance' (Holman et al., 2008) - displaying emotions which are not congruent with how the person is feeling internally:

"I can't have emotion, too much emotion, or it will devastate me"

"Sometimes you feel like crying in front of somebody...I think I should, you should just suck it up and not show those emotions necessarily at work. Because, you know, people may perceive something that you aren't comfortable [with] if they don't know you very well. So emotions in general can be a sign of weakness".

"Maybe it's the nursing mentality, but it's kind of like you just have to separate your emotion and get back to your work. And deal with whatever you're feeling when your shift is over. ... I quickly pulled it together and I just went on with my night".

Such emotional dissonance has been associated with burnout in HCPs as it increases emotional exhaustion (Fiabane et al., 2019). This subtheme therefore suggests that pressure to remain 'professional' affects HCPs' initial reaction to patient deaths at it dissuaded them from expressing their emotions which in turn can have negative implications for their wellbeing.

### Subtheme 2: Role-models

As participants frequently referred to role-models (also sometimes described as 'good leadership') influencing their emotional expression, this is included here as a distinct subtheme. Whether participants viewed showing emotion as a positive or negative seemed to be linked to the role models around them, with many referring to how they looked to more senior colleagues for cues on whether it was ok to show emotion and spoke of the benefit of having a role model who normalised this:

"When my first patient died, my resident—who I just think was totally great— he had tears in his eyes [which said to me], "Everyone goes through the emotions I'm going through right now, whether it's your first patient or your hundredth." He was very professional, very informative, and very helpful to the family. But he was emotionally attached to what was going on, and I think that that was really key. I guess that kind of changed my idea of being professional".

"I would love to see a round table with a few staff going, "This is how I deal with things when a patient dies. This is how I dealt with it when I was more junior. This is how I've learned to deal with it. Yeah, I feel sad. Yeah, I feel guilty. Sometimes I cry." So, you know, just a little bit more honesty about how they're dealing with it and not so much stone-faced".

"There's that subconscious idea that maybe you should be professional, or tough. Or, you look and see, "How are they acting? I should kind of act in the same way."

Such role-models could be both positive and negative, and influenced not only how the HCP reacted to the patient death at the time but also informed the attitudes that they developed themselves regarding whether emotional expression was appropriate. The following extracts highlight the fact that the presence of a positive role model directly affected participants coping responses, and that an absence of a role model could have lasting negative consequences for the HCP:

"The most important thing was the leadership at the top, was our attending and how he dealt with these issues. I think that if he had been very clinical and detached, it would have signalled to me . . . that's my role model, that's how I'm supposed to act".

"Role models were significant in the nurse's learning and response to the death event. If a role model was missing or emotionally unavailable, the nurse was confused as to how to understand the experience; unfortunately this way of experiencing patient death became "normal" for the nurse. A positive role model helped the nurse develop effective coping responses".

Others described how they could be made to feel that they should not show that they were upset at this would be unprofessional or would prevent them moving on to provide care to another patient.

"My educator, she almost got a bit annoyed that I was getting so upset because I should be treating the patients".

Sometimes the message given by role-models was not clearly positive or negative, but rather dismissive in the form of a lack of acknowledgement of how the HCP would be feeling after witnessing the patient death. Participants described feeling frustrated that their feelings were not recognised:

"I thought 'Are you not recognising what is happening or how I'm feeling about this?"

"I feel like my clinical instructor could have talked to me about the experience and at least asked how I was feeling about the situation".

A number of participants described wanting their superiors to act as positive role models when it came to displaying and talking about emotions following a patient death:

"I think what we need is guidance from more senior physicians. And I feel like many of us probably aren't comfortable going to them because... they don't talk about that stuff...Patients die all the time. There's bad outcomes all the time and nobody really sits down and talks about what's that like for them. Why don't we ever really sit down and talk about the emotional toll that... this work takes on us?". "I haven't seen my supervisors grieving; I don't think professionally we've been that open about it. Because you're a trainee, you're trying to just reciprocate or repeat, replicate what you've seen because that's the right thing to do. You learn that for pneumonia you give this antibiotic, for this you give this, and so we also learn that when someone dies you do the following.... I've never seen staff crying together. I've never seen them go to the office and hold each other's hands and cry through it".

The clear presence of this subtheme in the data suggests that role models are a key factor influencing HCPs' reactions and coping responses to patient death. This is consistent with existing research which has concluded that good role modelling enhances HCPs' learning and development (Peterson et al., 2010).

### Subtheme 3: Keeping Busy

A third subtheme was labelled 'keeping busy', as it was common for participants to describe how they would avoid showing emotion by turning to a practical task to distract themselves. Sometimes this was through their own choice:

*"I kept busy and tried not to let myself have time to think of anything about the patient".* 

"[I would] not let it get too deep. [I] distanced myself from it emotionally. I tried to put it out of my mind. I tried to get busy and not think about it after a while, didn't want it to be the only thoughts I had".

"I coped by staying busy with other responsibilities. Staying busy made it easier to accept his death".

Other participants described how keeping busy was less of a choice on their part, but rather due to pressure that they felt from others or from the demands of their role:

"I guess no one kind of tells you how to deal with it, or what to do with those emotions, and who to go to, and no one quite gives you the—the break that you need to sit down and talk things through. You're just expected to perform. You have a job. You have a responsibility. You're expected to move on. So you kind of—you do move—you make yourself move on, but you certainly don't deal with it, right?". "We don't get to breathe. We move on. If someone does die in the emergency department, I still have 30 people that I haven't spent time taking care of...Like I have to run back and make sure that the 30 people that I was ignoring... hasn't died on my—while I was there too and hopefully someone took care of them. And then to figure out all of those like you just move straight on. Um, and there's no back up. No. You can't call anyone to come in and do it. You just keep going. There's no, you know, there's no back up. Sometimes you get to debrief and sometimes you don't. You just kind of move on, so...".

"Because there's a lot of guilt about us even not showing up for work because we're sick. Let alone like because we can't deal with something that happened on our shift...I still think there's a lot of guilt and pressure for us to just do it. Suck it up and do it anyways and move on. And that's just not recognizing that we're human".

These synthesis findings suggest that if the HCPs felt unable to express their emotions, and felt unsupported, this intensified the distress already caused by the patient death. This is important as we know that when medical students feel forced to internalise and hide their feelings of grief following a patient death, they are more likely to experience mental and physical health issues (Moutier et al., 2016; Sharma, 2017). This finding adds an important piece of information to existing evidence which has recommended that HCPs have access to debriefing following experiencing a patient death (Kelly & Nisker 2010; Ratanawongsa, Teherani & Hauer, 2005) as these findings show that it is not only the provision of debriefing opportunities, but whether HCPs feel able to seek out this and to show emotion, which in turn appears to be dependent on the presence of good role-models. This is in line with Kelly & Nisker's (2010) point that "this [sharing of emotion] may be challenging if formal debriefing opportunities are not part of the culture of undergraduate medical training" (p. 427) and gives further weight to previously highlighted concerns that the importance of debriefing following a patient death is not emphasised in medical students' training (Serwint, 2004; Shanafelt et al., 2012; Sharma, 2017).

### 3.6.6 Theme 4: Past bereavement experiences and relatedness to patient

This final theme captures the psychological factors of the HCP's past experiences of death and how this can influence how they perceive patient death. These two aspects of this theme are interlinked as the most common experience described by participants was that the patient death brought up feelings from a past bereavement experience because they saw similarities between the patient and their relative, and/or the patient and themselves.

Some participants spoke of being reminded of their family members death and how this brought up difficult thoughts and feelings which they needed to cope with on top of the patient death:

"...it really affected me 'cause, I wasn't present for my grandfather's death. It had happened about 6 or 7 months ago... So I kind of learned through that experience... it kind of felt like I was at the bedside of my grandfather".

"He was so much like my Granddad, who had died just before I came to uni, I think that is why I got so close to him".

Sometimes these reminders were not about a bereavement but the fact that the patient shared characteristics with the HCP's relative leading them to think "this could have been my.."

"I was shocked. Again, I think it was mostly because he was so close to my Mum's age, and so close to my Dad's age. And it really gets you thinking about a lot of things".

"Two out of the five participants described the patients as being triggers to thoughts and emotions relating to their own relatives".

"In six (19%) cases, the students' emotional reactions seemed tied to how the patient reminded the student of someone to whom they were close".

"I noticed mainly that [how I react] is a matter of age, 40s, my parent's age, I'd be devastated".

"She was already terminal... but you relate more to this. You start thinking of your grandma and your aunt".

Patients' deaths who were of a similar age to the HCP or who had similar family structures to them (such as having children the same age as the patient's) were often described as more difficult to accept and cope with. This appeared to be mainly because it served as a stark reminder that death can happen to any of us at any time regardless of age and this made the experience and their emotional reaction more intense:

"I felt really bad... the patient's daughters were more or less my age and... I don't know, you empathize, you put yourself in their shoes and then the experience becomes even more intense".

"I always think [this could have been my husband]. When I have patients who are around my age it could very well be anyone of us...".

"It was the first time I saw death ... I thought about the family because the death was unexpected, so I started to relate it to my family, I thought about death, the idea of death".

This theme demonstrates the importance of HCPs' own bereavement experience and life circumstances being considered when supporting them to cope with patient death. These findings provide additional evidence to complement existing research suggesting that supporting nurses to manage their own bereavement experiences can be effective in reducing burnout (Dorz et al., 2003).

### 3.6.7 Influence of Ward Culture

Even though the research question for this systematic review and meta-synthesis focused on psychological factors, it was impossible to ignore the environmental factors which were evident in this analysis. All psychological factors and coping strategies throughout themes 1-3, were influenced by the wider ward culture which the HCP was working within. In this section this wider context and how it relates to each theme will be discussed, as acknowledging this environmental influence is instrumental in producing real world application and providing practical recommendations.

### Individual Death Event Appraisal and Ward Culture

Individual appraisal is influenced by the environment and messaging that a person is working in (Durak, 2007; Moos & Swindle, 1990). A frequently recurring example in this study is participants holding the belief that patient death constitutes a failure both on their part and that of the system they are working in. This in turn led them to appraise the patient death event as a personal and professional failing resulting in self-blame and guilt. This attitude originates from, and feeds back into, the ward culture, and wider training culture, that the HCP is working within.

### Emotional Expression and Ward Culture

The behaviour of role models and whether HCPs 'kept busy' rather than expressing emotion was both informed by, and in turn created, the wider ward culture around emotional expression. Ward environments described by participants ranged from giving the message that showing emotion would be unprofessional, through to supportive environments offering regular debriefing opportunities, and in the best examples, wards which included space and time for post-mortem rituals following a patient death. Such rituals were usually in the form of care of the body tasks such as washing and laying out. This provided a means of the HCP being involved in a task which showed respect to the deceased, gave them time to process the event, reflect, and informally debrief with a more experienced colleague, therefore providing a learning opportunity and encouraging positive reframing of the death event.

## Use of Engagement Coping and Ward Culture

Whether participants used engagement coping strategies depended on psychological factors such as perceived availability of social support and the HCPs' own beliefs about whether asking for help constituted being 'unprofessional' or 'weak', but also the ward culture they were working within. For example, if they perceived that there was a general message of 'if you ask for support you will be supported', then they seemed more likely to seek out social support and debriefing opportunities. If on the other hand they felt, or had witnessed others, being dismissed, they were more likely to use disengagement coping strategies such as avoidance rather than engagement coping strategies.

# 3.7 Discussion

# 3.7.1 Meta-Synthesis Findings Overview

This systematic review involving 601 HCPs from 11 countries working in hospital settings identifies key psychological influences of reactions and subsequent coping strategies to early-career patient deaths. The data collected via this review's search strategy was relevant to the objective of this review – 'what are the psychological influences on HCPs' initial reactions and coping responses to early career patient death events?' and addresses this question as follows.

How HCPs react to, and cope with, early career patient death events depends on a number of key individual and interpersonal psychological factors. How the HCP personally appraises the death event, their past experiences of death, and whether they use engagement coping strategies play an important role, in turn influenced by those around them in terms of the presence of role models, whether peers validate their emotional reactions and the availability of debriefing opportunities. The majority of these psychological factors are affected by the wider ward culture, meaning that it is not possible to focus on these factors, or enact effective improvements, without taking this into account.

These findings have implications for training and practice, providing recommendations regarding the importance of role model and debriefing availability, the structure of placements, training and debriefing sessions and the necessity of considering the influence of wider ward culture.

# 3.7.2 Discussion of Findings

Emotional expression, including whether HCPs felt able to display emotional reactions to patient deaths and whether their colleagues and superiors role-modelled that this was acceptable, was the most prominent theme identified in this review. Findings suggested that if the HCP felt they had to hide how they were feeling, for example by keeping busy, this could add stress to what was already a difficult and highly emotive experience. HCPs often spoke of looking to their role-models behaviour to inform their own, and that having positive role-models was important both to their wellbeing and to maximise their learning. This aligns with existing

research which has found that role models play an important part in helping medical students cope with the negative emotions and professional 'detachment' caused by their first experience of patient death (Kelly & Nisker, 2010; Kumar, D'Souza & Sisodia, 2013), that experiential learning is enhanced by the presence of positive role models (Peterson et al., 2010) and that good role modelling and pastoral care by mentors is vital to student nurses' development (Terry & Carroll, 2008).

However, the focus on psychological factors in this review highlighted that the presence of a positive role model alone is not sufficient to ensure a positive experience, but rather that if there is a combination of a perceived supportive environment and role models who can demonstrate to others that it is ok to express emotion without this detracting from their 'professional' persona, this combination is the optimum in terms of enabling early career HCPs to feel supported and able to express emotion during and following a patient death.

This finding has implications for practice, as it demonstrated the impact that different educational structures within the ward environment can have on the HCP's wellbeing and learning. When considering who constitutes a positive role model in these hospital settings, in this study it was usually a senior colleague whom the early career HCP respected and had an existing relationship with; they were familiar with their ways of working and felt able to speak to them following the event about the experience. It was clear in descriptions from some participants that the structure of their training and the environment they were in did not facilitate the presence of positive role models – for example some described how they did not have an existing relationship with the consultant prior to observing them at the patient's death, therefore making it unlikely that the HCP would feel able to turn to them for emotional support and would be more likely to feel pressure to 'remain professional'. This may be particularly relevant to trainees, who were the focus of this review, or other HCPs who are rotating through different placements and so who may be new to the culture of the ward environment and unfamiliar with support options.

This is a learning point relevant to how trainee doctors and nurses' inductions and ward placements are organised – it may be beneficial, particularly when thinking about death competency development, for them to be given the opportunities to get to know their colleagues and supervisors before being in a patient death situation

with them, and even to have a 'pre-brief' around patient death events prior to them being in the situation. Prebriefing has increasingly been used as one of three key stages in healthcare simulation training, along with debriefing and the learning scenario itself, and has been shown to benefit trainee HCPs by preparing them both for an optimal learning experience and ensuring psychological safety during the simulation (Page-Cutrara, 2014; Rudolph, Raemer & Simon, 2014). The findings of this review suggest that there could be a role for prebriefing in supporting HCPs to feel supported during and after a patient death event, as well as potentially increasing the ability of HCPs to view the event as a learning experience.

Whether the HCPs in this study viewed a patient death event as a learning experience was another clearly identified theme in this review, highlighting how similar events can lead to very contrasting responses and coping strategies. A key psychological factor seems to be individual appraisal of the event, which highlights how the same patient death event can lead to different responses across HCPs not only in the same department but in the same room at the time of the death. This is consistent with theories of cognitive appraisal which explain how individuals experience different responses to the same event due to different evaluations and interpretations of the event (Hwang, 2006). A common example was that a trainee doctor or nurse could be present at a patient death to observe and could either be left with thoughts that they were privileged to have witnessed a valuable learning opportunity, or with guilt and self-blame, depending on whether they appraised the event as being something within their control, something that was important to their professional development and/or a situation in which they should have taken action to prevent the death. Therefore, we can infer that how the person interpreted the event (their appraisal) and their role in this is a key factor in how they respond to and cope with the death. This is supported by existing research which has suggested that event appraisal influences HCPs' emotional responses to patient death (Kessler et al., 2012).

More specifically, a key concept from event appraisal theory, challenge, recurred throughout the data and can be used to summarise the 'patient death as learning opportunity' theme findings. As previously discussed, challenge is one of three aspects of 'psychological hardiness' or resilience (Kobasa, 1979, 1982) and challenge appraisals are known to reduce the likelihood that a person will view an

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event as a threat to their wellbeing resulting in better event outcomes (Skinner and Brewer, 2002).

These findings – the importance of individual appraisal and more specifically the role of challenge appraisals, have implications for debriefing practice, as it suggests that it would be insufficient for a debrief to be restricted purely to the facts of what happened without considering how each HCP has personally interpreted the event. This lends support to previous research that has noted potential issues since there is no single accepted definition of 'debriefing' and could offer a possible explanation as to why the structure and content of debriefing sessions have been judged to be inadequate by HCPs in previous studies (Tan, 2005). It may be beneficial for individual appraisals of patient death events to be explored at the start of a debriefing session so that the rest of the session can be tailored to the individual needs of the HCPs following the event. Debriefing without understanding the individual HCPs perception of the patient death and their role in this could increase the risk that they may find the debriefing session inconsistent with their views and therefore invalidating.

This was a further key finding from this meta-synthesis – if the HCP sought support, either informally from colleagues as social support or formal debriefing, but this was not perceived as validating of their experience and emotions, this acted as an additional stressor on top of the patient death itself. These findings lend further support to existing studies which have emphasised the importance of support and validation when attending to the emotional impact of patient death events on HCPs (Karger et al., 2015; Schulz-Quach, 2018) and which have noted that engagement coping appears to facilitate the development of resilience following patient death events (Schulz-Quach, 2018).

We know that engagement coping strategies are associated with lower stress levels in HCPs (Chao, 2011), and the identified importance of engagement coping in this review has implications for how we support HCP's wellbeing. It appears from these findings that there is value in facilitating and encouraging HCPs to use engagement coping strategies but that in turn it is vital that when they do, they are met with both formal support opportunities such as debriefing, and validation from their peers. For both of these things to be available we must further consider the influence of ward culture, found to be an overarching influencing factor in this review. Hospital environments should build patient death debriefing opportunities, such as 'death rounds' (Hough et al., 2005) into training structures, but also consider the wider ward culture. A ward culture which dissuades HCPs from voicing their support needs and which gives the message that emotions following a patient death are unwelcome, invalid, and unprofessional, is likely to compound the negative effects of a patient death event.

A further individual psychological factor which influenced HCPs reaction to a patient death was their past bereavement experience, for example if a patient resembled a family member who had died. A common example of this was participants describing how a patient was like their grandparent (since participants in this study were trainees and therefore likely to be younger), and how this could cause them to experience a stronger emotional reaction because they a) felt a connection to the patient and/or b) it reminded them of being present at the death of their relative.

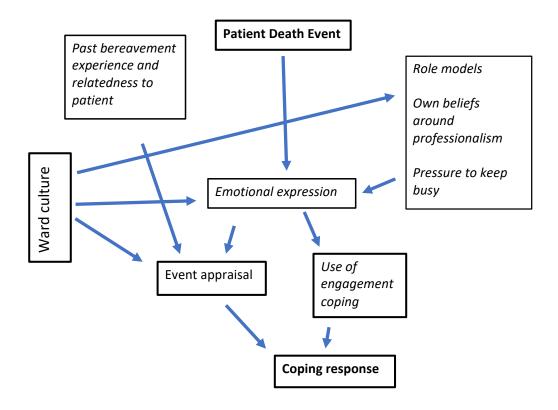
Finally, even though the focus of this review was on psychological factors, it would be a misrepresentation of the data to ignore the clear effect of ward culture on many themes found in this review. This finding is consistent with previous research which has reported that HCPs' work environment influences their patient death coping responses (Povedano-Jimenez et al., 2020).

In this study, the impact of ward culture was particularly salient within the theme of emotional expression, namely that the culture of the work environment affects how freely staff feel able to express emotion relating to patient death. Again, this supports previous research, which has demonstrated that HCPs' work environment affects emotional expression (Whitehead, 2014) and that states that the onus should not purely be on the HCP themselves to be aware of their emotions following a patient death and to reflect on these, the work environment must also acknowledge this and 'build in' the time and space for them to do so (Sharma, 2017).

It may be useful to view past bereavement experience, use of engagement coping strategies, and emotional expression, along with wider ward culture influence, as mediating factors between initial HCPs' reaction and response to patient death and their individual appraisal and coping response to the event. A suggestion of this model is shown below in figure 4.

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Figure 3 Interaction of Factors Involved in Death Competency Development



### 3.7.3 Merits of Review

This review goes further than existing research by providing important insights into psychological factors which influence and underpin HCPs' reactions to patient death events and their subsequent coping strategies. This study therefore aids understanding of how HCPs make sense of and respond to death events, with findings having implications for informing how early-career HCPs are supported following the death of a patient in their care. Evidently, more experienced HCPs also need support following a patient death, though this review specifically highlights how early-career HCPs who are not only new to the experience of a patient dying, but also to the wider ward culture, can be particularly negatively impacted. For these individuals, there appears to be a key window of opportunity to build support around encouraging engagement coping and challenge event appraisal and facilitating emotional expression.

This review clarifies the extent of existing literature as the researcher found what initially appeared to be a significant number of studies related to the research

question, however the data extraction process highlighted the fact that many studies which state in their aim that they are investigating HCPs' reaction to patient deaths do not actually do this. Studies were excluded on the basis that they set out to ask HCPs about their experience of a patient death, but then used methodology which did not fit this aim, such as an interview schedule asking participants about their experience of providing care to a dying person and their family as opposed to the participants experience of patient death. This observation is noteworthy as it means that there is not as much existing research focusing on patient death events as may initially appear to be the case. Prior to this review previous literature reviews, such as that by Schulz-Quach in 2018, had identified that most existing research had focused on HCPs' responses to providing end of life care during the process of dying rather than to patient death events themselves. This review has demonstrated that 4 years later in 2022 this is still the case, and that there remains a gap in the literature regarding how HCPs respond and cope when their patients die. This review provides an in-depth and novel contribution which begins to fill this gap in our knowledge.

#### 3.7.4 Strengths, Limitations and Methodological Considerations

This systematic review and meta-synthesis utilise a rigorous method to identify, appraise and synthesise the existing qualitative literature on how HCPs react to and cope with patient death events. Importantly, it pinpoints several key psychological factors which should be considered in any future interventions aiming to support HCPs following a patient death.

Whilst considering the contribution of this review it is also important to acknowledge several limitations. Firstly, it is not possible to entirely remove the possibility that relevant studies may have been missed during the search process – it is well-known that it can be difficult to comprehensively retrieve qualitative studies in a systematic review (Wong, Wilczynski & Haynes, 2004). The search strategy used for this systematic review was designed to minimise these issues as much as possible, with all reasonable steps taken to reduce the likelihood of this occurring. The results of this study may also be affected by publication bias, as previously mentioned it has been suggested that there is under-publication of studies focusing on death events as opposed to the dying process (Kumar et al., 2013).

Secondly, 6 out of 21 studies included in this review were judged to be of low quality via the CASP checklist, with only two studies reporting theoretical underpinnings to their methodology and many using research methods which did not fully map onto the study aims. As existing literature specifically focusing on patient death is relatively sparse, it was felt that it was more valuable to include these studies to enable a broader participant pool and qualitative dataset whilst acknowledging this limitation, than it would have been to exclude these studies from the review. This did not mean however that studies which could have affected the reliability of the review were included, for example a study which was found to contain duplicated data from another paper was excluded from the review.

It was notable that during the selection process many studies fitted the inclusion criteria of the aim being to look at response to patient death however were then excluded because the study focused on dying (death as a process) rather than death itself (death as an event). This echoes findings from a review by Schulz-Quach (2018) which explored the phenomenology of death in HCPs which reported that a minority of studies focused on the death events itself with most existing studies focusing on the process of dying, strict inclusion and exclusion criteria meant that this review does not fall into this trap. This is symptomatic of an ongoing philosophical debate, discussed in greater detail in the previous chapter (Chapter 1 Introduction and Background), around how to define death within death studies research – whether it is an event or a process. There is therefore no 'right or wrong' way to approach this, however it does mean that a clear and consistent approach to defining death is required. This study maintained this throughout search strategy and study selection, data extraction and analysis, meaning that results can be taken to be a clear answer to the research question.

Thirdly, as this review only included HCPs, namely doctors, nurses, and physiotherapists, working in hospital environments the results cannot be generalised to other professions or volunteer workers, or to settings outside of hospitals. This represents a gap in the literature and future research is needed to explore how other health and social care professionals respond to patient death outside of hospital settings for example primary care workers, community workers, non-professional care workers and home care providers. As the findings of this review suggest that the environment in which patient death occurs is an important factor, it may be beneficial for future studies to compare findings with those conducted in hospital settings.

Finally, data from included studies were integrated in a meta-synthesis, with the benefits of this method being that it allows for the preservation of the content of included studies which facilitating a new, holistic understanding of the research area, in turn generating new insights and theory (Walsh & Downe, 2005). However, it is also important to acknowledge possible limitations of this approach such as the risk of the subjective interpretation of the researcher influencing the understanding of the data and subsequent analysis (Chrastina, 2018). This limitation was minimised in this study via the use of 'investigator triangulation' – having an independent reviewer validate a percentage of the data extraction and review subsequent theme identification.

Despite these limitations, this systematic review makes an important contribution to existing literature on how HCPs appraise and cope with patient death through key psychological influences. Of particular importance is the finding that it is not necessarily sufficient for support options to be present, such as debriefing opportunities, as the wider ward culture along with the person's own interpretation of the patient death event effect whether they will utilise these support offerings.

Beyond the influence of ward culture, as this review spans 11 countries it is also vital to consider the cultural context of these findings. Previous researchers have reported that the impact of culture on death attitudes has not been adequately explored (Bass, 2021), however existing research in this area has resulted in findings which demonstrate clear differences between 'Western' and 'Eastern' cultures in terms of death attitudes (Hui & Fung, 2008; Madnawat & Kachhawa, 2007). Broadly speaking the majority of countries included in this review are considered 'Western' cultures (USA, Canada, Wales, Spain, Ireland, Sweden, Mexico and New Zealand), with a minority being countries which are considered to be 'Eastern' cultures (Taiwan and Lebanon) or a mix of the two (Turkey).

It has been demonstrated that in Western cultures such as the USA there is a prevailing belief that "man can master nature" and that this can results in death denial and anxiety, whilst some Eastern cultures such as in Polynesia hold an overarching attitude of a complementary relationship between humans and nature. This, coupled with the cultural practices of open funerals involving family members of all ages seeing and touching the corpse of their relative, and funerals having no expectation of morbidity, can foster much higher levels of death acceptance (Howard & Scott, 1965).

When looking at the findings of this review it may be that difficulties HCPs had with expressing emotion, lack of role models with positive death attitudes, lack of peer validation and viewing patients' deaths as threats to self rather than learning opportunities are all symptomatic of the 'death anxious' Western cultures the majority of participants in this study were working in. However, similar death avoidant behaviours have been found in Eastern cultures for example Willemsen et al (2021) found that the cultural attitude of "death as a taboo", focus on 'family harmony', lack of acknowledgement of the importance of end of life care, negative cultural and spiritual view of death and general cultural practices of communication in China acts as a barrier to HCPs palliative care training (Willemsen et al., 2021). Such potential cultural differences are not distinct in the current study as the review didn't explore the literature through this lens, however these potential impacts of cultural context should be held in mind when interpreting these findings.

### 3.7.5 Relevance to Future Research

To the researcher's knowledge this is the first review exploring psychological factors of how HCPs react to and cope with patient death. The systematic review and metasynthesis were able to summarise descriptively the nature of existing data and synthesis this to provide new knowledge and extend our understanding of HCP experiences of patient death events. By identifying that there are common ways in which HCPs react to and cope with patient death events in hospital settings globally, this review provides a further foundation for future research to build on.

The findings of this review suggest that future research should focus on individual death event appraisal, as this was central to a) how HCPs reacted to and felt after the patient death, b) whether they then used engagement coping strategies and c) whether they believed it was justified for them to be feeling the emotions they

experienced. It would be particularly useful for this to explore the role of challenge appraisals as this was identified as being linked to more positive outcomes for HCPs. Secondly, it would also be beneficial for future research to explore the potential benefit of prebriefing sessions prior to HCPs being present at a patient death event.

# 3.7.6 Applications to Future Practice

This is a timely review due to the wider context of death and dying conversation within healthcare organisations which are currently happening in the UK and beyond. High profile reports, such as The Lancet Commission on The Value of Death, which was published in February 2022, have recently called for a 'rebalancing' of how we deal with death and dying, pointing to the fact that healthcare systems and cultures themselves do not generally facilitate death being 'done well'. The findings of this review may go some way towards explaining why several historical interventions which have aimed to improve HCPs' skills regarding death and dying have been unsuccessful and have not resulted in behaviour change (Connors et al., 1995; Doorenbos et al., 2016; Danis, et al., 1991, Schniederman et al., 1992; Song et al., 2010), as it demonstrates the need to address overarching psychological factors rather than purely focusing on individual skills. The finding that broader cultural change is needed within hospital settings for HCPs to engage in effective coping is in line with one of the key recommendations from the Francis Report (2013) which called for cultural change which promotes openness and transparency.

This review highlights possible areas where it may be more effective to target interventions to improve how HCPs deal with patient death for example not only increasing the quality and frequency of debriefing opportunities, but also ensuring the presence of positive role models and an awareness of the wider culture, particularly around showing and validating emotion.

## 3.7.7 Summary of Study Contribution

What is already known on this topic?

• The experience of being present at a patient death can have a profound and lasting effect on HCPs.

- The experience of a patient death, particularly the HCPs first experience of this, can be formative.
- HCPs can struggle to cope with the impact of patient death, and this can lead to burnout.

What this study adds:

- Goes beyond identifying how HCPs react to and cope with patient deaths to identify key psychological influences which are applicable to international hospital environments.
- HCPs' reactions to and coping strategies for patient deaths cannot be improved without considering wider psychological influences.
- Identifies useful recommendations for future research and practice, namely that individual appraisal of a patient death event, along with wider ward culture, should inform the support that is offered to HCPs.

Considering the findings of this systematic review and meta-synthesis, this thesis focuses on individual patient death event appraisal and looks at this in detail in relation to factors influencing the development of death competency. The following chapter presents a mixed methods study exploring the role of patient death event appraisal in the development of death competency in doctors, nurses, and EoL doulas.

## **CHAPTER 3: METHODOLOGY**

# **2.1 Introduction**

The aim of this chapter is to provide a detailed explanation of the researcher's stance and procedures, to enable the reader to understand and assess the quality of methods used to the point that they could in theory replicate the studies contained within this thesis and so that future research could learn from and build on the methods used here. The rationale for this choice of methods will be discussed along with procedures for data collection, analysis, and quality assurance, with the aim of providing the reader with the knowledge and tools required to assess the reliability, validity, and trustworthiness of this research. It is also important for qualitative, and therefore mixed methods researchers, to reflect on their own role in their research and clearly report their approach in line with good practice recommendations (Long, French & Brooks, 2020); therefore, this chapter also aims to introduce the concept of reflexivity, a tool which is used throughout this PhD to enhance the rigor, ethics, and transparency of this research process.

## 2.1.1 Covid-19 Pandemic Context

To ignore the social and environmental events surrounding any thesis would be to miss out a vital part of the context of the research, and this is especially true of this PhD which was completed during an unprecedented global event - the Covid-19 pandemic which brought unique challenges. This PhD began in June 2019, with the pandemic officially being declared in March 2020, therefore most of this research, and all data collection, took part whilst the pandemic was ongoing, through its peaks, and during restrictions such as national lockdowns. The researcher was also directly affected herself, with parts of this chapter being written whilst having Covid-19. This necessitated changes to the original PhD plan.

Search terms for the systematic literature review were being finalised when the pandemic began. The researcher paused at this point to consider what this meant for the direction of this PhD, including undertaking wider background reading to inform this decision. This scoping literature review identified the potential for a more focussed systemic review and meta-synthesis of published qualitative studies

relating specifically to HCPs' responses to patient death events and subsequent coping strategies.

Following on from this systematic literature review, the original plan was to conduct an online survey and follow-up qualitative interview study to inform design of a model of death competency development. Social distancing restrictions meant that the researcher was unable to conduct face-to-face interviews; the use of video software was considered however it was decided that data quality would be likely to be lost due to missing non-verbal information when discussing a highly sensitive topic. Also, one of the plans to mitigate the risk of participant distress was the fact that the researcher is experienced in talking to people about death and dying; had video interviews been used it would not have been possible to offer this support as well.

Considering this, the revised mixed methods study design became the online survey described in Chapter 4. The cross-sectional survey was developed to combine the planned qualitative phase with identification of possible predictors of death competency development. Changes to recruitment strategy were also required, with the original plan being to recruit via hospital research and development departments. This was no longer possible due to these departments prioritising Covid-19 research; social media was successfully used to recruit participants instead as described above. Further decisions were made about the number of data collection phases, as it was thought that the amount of qualitative data collected via the survey may be minimum due to participants own time constraints caused by the pandemic. However, this was not the case – participants generally provided lengthy descriptions of their experiences and so no additional data collections phases were required.

Finally, the value of the unique perspective of the researcher who is a trained EoL doula was recognised, leading to the inclusion of Chapter 5: Reflexivity, dedicated providing insight data regarding the exploration of this position and perspective.

The combination of these three methods – systematic literature review and metasynthesis, mixed methods cross-sectional survey, and researcher reflexivity enhances the triangulation within the approach to utilising mixed methods. Further to considering these required changes to original study design, it is important to also consider the effect this wider context may have had on participants as individuals as well as the data, and on death competency. A global threat to health, such as the pandemic, is likely to increase mortality salience in the population as a whole (Arrowood et al., 2017; Belanger, Faber & Gelfandbene, 2013), in turn increasing death anxiety and recent research has demonstrated that this was indeed the case for Covid-19 (Menzies & Menzies, 2020). In terms of what this means for this research, it may be that participants were less likely to report themselves as being death competent due to higher levels of death anxiety caused by the pandemic. As this was a global threat to health event the effects of this would have applied to all participants and so does not pose a risk of bias, however it is important to note when interpreting the results. For HCPs working on the 'front line', witnessing deaths from Covid-19 first-hand this is even more applicable.

#### 2.1.2 Researching Death Competency: Why and How?

The majority of research into death and dying to date has focused on the negative aspects of death attitudes, specifically death anxiety, with relatively little exploration of the positive side of death attitudes (Neimeyer, 2004), namely death literacy and death competency. Noonan et al., (2016) define death literacy as "a set of knowledge and skills that make it possible to gain access to, understand, and act upon end-oflife and death care options" which "is the result of engaged death education" (Noonan et al., 2016, p. 1). Whilst there is no debate that death literacy is an important and valuable concept, the focus on knowledge and skills is problematic. We know that providing HCPs with the knowledge and skills about good quality end of life communication is not sufficient for behaviour change (and therefore actual improvement and impact) (Dosser & Kennedy, 2014), and that HCPs' own death anxiety can cause them to avoid discussing the topic with patients (Clare, Elander & Baraniak, 2020), such avoidance means they rarely encounter situations to be able to demonstrate death literacy or to improve their death literacy. Therefore, the more helpful concept to focus on is death competency, defined as "a range of human skills and capabilities in dealing with death, as well as our beliefs and attitudes about these capabilities" (Robbins, 1994). It could be said that death literacy is the precursor to death competency as the former describes the skills and knowledge

whilst the latter refers to the practical application of these. By focusing on death competency, we can get to the heart of potential barriers to good quality end of life care and therefore increase the likelihood that the findings of this study will have real-world applications; ultimately it does not matter how much training is provided to a HCP if they still do not feel able to cope with the topic of death and dying and therefore avoid dying patients.

This summary of death studies research to date suggests and recommends that a) there is a need for research into death competency and b) present-day research in this area should aim to have both theoretical and practical relevance. This contrasts with much of the research to date which has lacked real-world application (Neimeyer, 2004). The aims of this PhD align with these recommendations as they focus on HCPs' experiences of patient death and how their appraisal of such events could potentially impact their levels of death competency, which has implications for their practice. It is useful to remind ourselves of the aims of this research at this point, to understand the rationale for the methodology and methods used and consider what these mean for the research design of the studies aiming to answer these questions.

### 2.1.3 Research Objectives

- To systematically review existing literature investigating psychological influences of HCP's responses to patient death events, including their appraisal and coping strategies.
- To conduct a mixed methods exploration of HCP's narratives of patient death events to investigate their appraisal of such events and their subsequent ability to develop death competency.
- To compare differences in patient death event appraisal according to professional training and identity focussing on traditional and non-traditional healthcare roles specifically doctors, nurses, and end of life doulas.
- 4. To identify potential predictors of death competency development following first experience of a patient death event.
- 5. To reflect on the process of conducting research into HCP's development of death competency from the perspective of a trained end of life doula.

As these questions include both individual appraisals of an event (their personal experiences) and a comparison of different roles and identification of predictor

variables, these research questions lend themselves to a mixed methods design. This chapter will introduce the theoretical and epistemological background of this research, followed by a detailed description of the research design and procedures used, including meta-synthesis, novel approaches such as the use of the Stress Appraisal Measure (SAM) (Peacock & Wong, 1990) in death event appraisal and use of the Coping with Death Scale short version (Galiana et al., 2019) in a population of HCPs including EoL doulas, and continuing reflexivity.

### 2.2 Mixed Methods

### 2.2.1 Why mixed methods?

Quantitative research methods align with the traditional 'cause and effect', deductive model of scientific research (Park, Konge, & Artino, 2020). They are built on the premise that we can objectively measure real-world phenomena by dividing them into smaller, manageable pieces to test a hypothesis and increase understanding using mathematical methods (Almalki, 2016). Whilst their strength lies in objectivity and accuracy through reducing opportunity for bias, quantitative methods have increasingly been considered reductionist (Shaw et al., 2019) as they are unable to capture the wider context including meaning, personal experiences and stories, *"for researchers who wanted to focus on making sense of human experience, how people communicate with each other, and how they operated within a social system, a different approach was needed"* (Shaw et al., 2019, p. 3).

Qualitative research emerged because of this need and are fundamentally about understanding individual experiences of a phenomena (Hayes & Singh, 2012). A qualitative methodology element is particularly appropriate when a research area requires further exploration as it allows investigation of participants personal experiences (Creswell, 2013) and lends itself to the development of new fields of study (Shaw et al., 2018). A qualitative element to this study is therefore appropriate as both these descriptions apply to the field of death competency research.

An answer to the increase in areas of health and social care research involving multifaced phenomena, and therefore requiring multifaceted approaches to broaden understanding (Andrew & Halcomb, 2006), emerged in the form of mixed methods approaches, which involves the use of a combination of qualitative and quantitative

methods across different research paradigms (Cresswell & Clark, 2007). Mixed methods methodology has increasingly been embraced by social science researchers as demonstrated by the publication of recent mixed methods reporting guidelines by the American Psychological Association (Levitt et al., 2018). This is a welcome development as until recently there remained a hierarchical view of guantitative and gualitative data within these studies, for example a systematic review of mixed methods studies published in nursing journals between 1998 and 2005 finding that qualitative data was viewed and presented as secondary 'add on' to quantitative research (Giddings & Williams, 2006). Rather than viewing mixed methods as simply a combination of qualitative and quantitative methods, mixed methods is its own 'third' research design with its own strengths and weaknesses. The benefits of mixed methods research are most evident in healthcare research, where mixed methods approaches are increasingly becoming a dominant research paradigm as it allows the exploration of complex, multi-dimensional research questions often found in the health and social care field (Doyle, Brady & Byrne, 2009).

A mixed methods approach was adopted for this study as this follows recommendations from previous research in the field of death competency and death anxiety. Neimeyer (2015) highlighted that over the past 25 years there has been a focus on developing and refining quantitative measures of death attitudes which has resulted in a lack of qualitative studies. The studies which have utilised a qualitative approach have demonstrated the importance of capturing nuances of personal experiences alongside quantitative data – for example Dosser and Kennedy (2014) found that whilst nurses rated themselves as being more confident in having end-oflife conversations on a quantitative survey, semi-structured interviews uncovered the fact that this did not translate into behaviour change, as participants were avoiding having these conversations with patients. This provides support for Neimeyer's suggestion that death and dying research should turn to mixed methods approaches to "capture the richness of human belief systems about death without sacrificing the precision of quantitative research" (Neimeyer, 2015, p. 270).

Mixed methods were also appropriate as this study is concerned with both the 'micro' and 'macro' view of death competency within hospital settings. That is, it aims to

explore both individual HCP's experiences of patient death, their appraisals of these events, and their death competency - these subjective and personal experiences can be referred to as the 'micro' level. It also aims to 'zoom out' and view these experiences and personal attitudes to death against the context of the person's role, and therefore their training background – looking at wider patterns, cultural and structural explanations, which can be referred to as the 'macro' level. As this study is exploring two notoriously complex issues - death and dying, within the context of multi-layered healthcare systems, by using a mixed methods study design it was possible to explore measurable concepts such as death competency, whilst also understanding the detailed personal experiences of a very sensitive life event. A mixed methods approach provides a means of moving between and "transcending" these levels (Kelle, 2001) and this therefore makes it an optimal choice for this study. This enabled access to a whole picture, greater than the parts that quantitative or qualitative methods could produce alone; as Fetters & Freshwater (2015) said, mixed methods are not about combining different data sets but integrating methods to allow production of more than either individual component could alone. As the research questions themselves require a combination of qualitative and quantitative methods - to identify possible factors of death competency development it is necessary to statistically explore these factors in relation to quantitative measures of death competency; to explore individual HCP's appraisals of patient death events requires qualitative data collection and analysis, mixed methods were deemed most appropriate.

### 2.2.2 Mixed Methods Designs

Mixed methods approaches have been broadly split into four main types: triangulation, exploratory, explanatory, and embedded design (Cresswell & Clark, 2007). These designs are briefly summarised in Table 1 below along with a statement as to the appropriateness of the design in relation to this study.

| Mixed Methods<br>Design | Description  | Appropriateness for this Study  |
|-------------------------|--|---|
| Exploratory             | Qualitative data is used as<br>the foundation and informs<br>data collection of the<br>quantitative phase. | Qualitative and quantitative<br>data were collected<br>concurrently in this study |

#### Table 9 Mixed Methods Designs and Rationale

|               |  | meaning this design is not best suited.  |
|---------------|--|--|
| Explanatory   | Quantitative data is used as<br>the foundation and informs<br>data collection of the<br>qualitative phase.   | Qualitative and quantitative<br>data were collected<br>concurrently in this study<br>meaning this design is not<br>best suited.  |
| Embedded      | Either quantitative or<br>qualitative data is used in a<br>secondary supportive role.<br>Primarily used in<br>quantitative studies where<br>there is limited qualitative<br>data available.                                      | This study was designed to<br>collect a large amount of<br>qualitative data meaning<br>this design is not best<br>suited to this study.  |
| Triangulation | Involves the use of<br>qualitative and quantitative<br>methods to generate<br>complimentary yet different<br>data on the same topic,<br>which can then be<br>integrated to inform<br>interpretation (Cresswell &<br>Clark, 2007) | As data are collected via a<br>systematic literature<br>review, qualitative open-<br>text response questions<br>and quantitative<br>psychometric scales, this<br>design provides the<br>opportunity for triangulation<br>between underpinning<br>knowledge and theory<br>empirical data. Making it a<br>good fit for this study. |

Based on this rationale, a triangulation mixed methods design was used for this study. This approach goes beyond simply integrating qualitative and quantitative data to enable comparison between the two but allows the creation of a comprehensive explanatory framework (Mertens & Hesse-Biber, 2012) allowing the research questions to be addressed more fully than through using qualitative or quantitative methods alone.

Mixed methods is, however, about more than the combination and integration of methods, but also the merging of ontology and epistemology. As Shaw (2018, p. 232) puts it "expressed quite simply, in mixed methods research it is not that different methods are being mixed, but it is paradigms, i.e., ontologies and epistemologies, that are being mixed". It is therefore important that we explore the research paradigms underpinning this study next.

#### 2.3 Research Paradigms: Ontological and Epistemological Stance

The development of new theories involves more than just the presentation of new facts; it requires new ways of looking at and interpreting information, and to do this we need to be aware of the 'lens' we are viewing the information through. It is impossible to view and hold all the information and complexity of a research area in focus at once, and therefore a necessary part of research is to reduce the focus down to a manageable area. To do so, the researcher must make decisions and assumptions regarding what is taken to be a factual foundation for the research, what is to be explored and how to go about this, and how they will know when new, valuable knowledge has been discovered and what this would look like. It is vital that the researcher recognises the role that their own standpoint and beliefs have in this process.

This process involves two key philosophical concepts – ontology and epistemology. Ontology refers to the nature of reality and is often discussed on a spectrum between objective reality, which exists independently of the observer, and subjective reality such as that which is socially constructed between people and through human perception (Bryman, 2004). Ontology is closely linked to epistemology, the theory of knowledge, which describes how we know what we know and how we can differentiate between true knowledge and false knowledge. Ontology covers the 'what is out there for us to know?', epistemology the 'what and how can we know it?' and methodology the 'how can we go about learning it?'.

To examine and explain the epistemological stance of this research, we need to look at the above mentioned ontological 'spectrum' in a little more detail. When approaching the subject of death competency, there are concepts operating on both individual and social levels (Neimeyer, 2015). This study takes the position that the individual HCP is experiencing a phenomenon (patient death), through the subjective lens of their own appraisal of the event, and that we can measure their death competency to understand causations, whilst simultaneously believing that the HCP's experience is influenced by the culture of the hospital environment and their professional role identity. It is impossible to escape the subjective nature of death attitudes, and particularly of individual appraisals of death events which are inherently subjective. At the same time, it is possible to begin exploring death competency by using self-report psychometric scales, as this measurement may tell us important information about death competency levels, changes across time and between different groups. The study of death competency requires some reduction of subjective concepts into measurable variables.

This means that different parts of the current research question lend themselves to both a research paradigm which believes that human experiences can be objectively observed and measured – a positivist stance, and others to a stance which holds that reality exists independently of human constructs, that knowledge is a matter of perspective, and therefore cannot truly be observed – a subjectivist stance. Critical realism (Bhaskar, 1979) brings together these two viewpoints – stating that reality exists independently of human constructs and therefore cannot be truly observed whilst also acknowledging that the world as we know it is constructed through human perspectives and experiences, which are observable and therefore can be measured. It is particularly concerned with events and processes within events (Easton, 2010) To summarise, the researcher is taking a critical realism stance, believing that death events and the appraisal of these are influenced by structures, social phenomena including relationships and language and other event processes, and our study of such events is therefore fallible, yet still amenable to empirical study and that this is a valuable endeavour.

## 2.5 Methods of Investigation

## 2.5.1 Design

Data were collected via a mixed methods, cross-sectional survey which was created and run using Qualtrics, an online survey platform. This allowed participants to follow a link to complete the survey. Quantitative and qualitative data were collected concurrently from each participant within the same survey.

The survey employed quantitative data collection methods in the form of validated scales - the Coping with Death Scale (CDS) Short Version (Galiana et al., 2019) and Stress Appraisal Measure (SAM) (Peacock & Wong, 1990) and a series of statements requiring Likert scale responses. Free text response boxes were used alongside these scales to collect qualitative data on individual experiences of death events and individuals' appraisal of these. This methodology was in line with the

epistemological underpinnings of this PhD as it asked participants to describe their subjective experience of the phenomenon of patient death.

Potential predictors of death competency were informed by existing research, detailed in the Introduction chapter of this thesis, and the systematic literature review described in Chapter 2. Dependent and independent variables were as follows:

Dependent Variable: Death Competency (Measured using CDS Short version)

Independent Variables:

- Appraisal of first experience of death (Measured using the SAM with subscales challenge, threat, centrality, controllable-by-self, controllable-byothers, uncontrollable-by-anyone as separate IVs)
- Professional role traditional vs non-traditional
- Experience (measured by time in role)

# 2.5.2 Psychometric Measures

# Death Event Appraisal

The Stress Appraisal Measure (SAM) is a self-report measure for cognitive appraisal developed by Peacock & Wong (1990). The SAM is built on the cognitive-relational theory of appraisal and transactional model of stress and coping (Lazarus & Folkman, 1984) which describe appraisal in two phases; primary appraisal refers to the immediate judgement we make about an events' impact on ourselves as an individual, for example 'is this event significant to me or irrelevant?'. Secondary appraisal follows this and involves our judgement about whether we have the necessary coping resources to deal with this event, for example 'will this event exceed my coping resources?'.

The SAM measures six appraisal dimensions, three primary appraisal measures, and three secondary appraisal measures, as well as overall perceived stressfulness. These are detailed in Table 2 below. Our appraisals reflect whether we believe that we have the efficacy to cope with and meet the demands of a situation (Peacock & Wong, 1990), which makes the SAM a 'good fit' alongside the measurement of death competency, which reflects an individual's judgement of their self-efficacy for dealing with a situation related to death and dying.

| Appraisal Phase        | Subscale               | Description  |
|------------------------|------------------------|--|
| Primary Appraisal      | Centrality             | Refers to an individual's perception<br>of how important an event is for<br>their personal wellbeing. Has been<br>shown to be a distinct appraisal<br>dimension, with the measure<br>therefore being suitable for<br>application to a wide range of<br>events, both past and future.   |
|                        | Threat                 | Psychological threat is used to<br>describe the appraisal that an<br>event poses a danger to oneself or<br>in-group, and/or that it conveys<br>negative information about the self.<br>Appraisal of threat usually leads to<br>anxiety, and it is particularly<br>relevant when looking at appraisal<br>of future events.  |
|                        | Challenge              | Along with commitment and<br>control, challenge is one of the<br>concepts included in the wider<br>term 'psychological hardiness' or<br>resilience. Challenge refers to the<br>viewpoint that change and<br>situations which draw on coping<br>resources are opportunities for<br>growth rather than threats. High<br>challenge scores reflect a<br>willingness to tolerate ambiguity<br>and flexibility in response to<br>change. |
| Secondary<br>Appraisal | Controllable-by-self   | Refers to the person's belief that<br>they can influence the outcome of<br>the situation, linked to locus of<br>control.   |
|                        | Controllable-by-others | Refers to the person's belief that<br>the situation can be influenced by<br>those around them. It has been   |

 Table 10 SAM Subscales (Peacock & Wong, 2009)

|                          |  | found to be correlated with internal<br>locus of control, which may seem<br>contrary, however "a high score on<br>the controllable-by-others scale<br>reflects the perception that others<br>can serve a useful support<br>function". |
|--------------------------|--|---|
|                          | Uncontrollable-by-<br>anyone   | Refers to the person's belief that<br>the situation cannot be influenced<br>by themselves or others.  |
| Overall<br>stressfulness | The SAM also provides an overall measure of the perceived stressfulness of an event. |   |

The challenge subscale of the SAM may be particularly relevant to this research as the concept has been developed and refined based on testing in "high reliability occupations", that is, "those in which demands are high and failure can be catastrophic" (Carpenter, 2016, p.272). This includes HCPs as they are often in situations where their decisions can impact whether their patient lives or dies.

It is important to note that the SAM was originally recommended for use with future events, however despite Peacock and Wong (1990) stating that they planned to develop a model for appraisal of past events this has not occurred and there are no measures developed for this purpose. Carpenter's (2016) literature review reported only five measures of event appraisal (Carpenter, 2016), with no further measures developed since. Out of these existing measures the SAM is the most appropriate scale available for this research for the reasons detailed above. This is therefore a novel use of the SAM both in relation to the type of event being appraised (death) and using it to gain insight into appraisal of past events.

The SAM has been found to have good internal validity, with its subscales measuring six relatively distinct dimensions of appraisal, with a mean intercorrelation of 0.22 (Peacock & Wong, 1990). Previous studies report adequate Cronbach's alpha coefficient values for the SAM from 0.74 to 0.90 (Gan & Anshel, 2006; Gan, Anshel & Kim, 2009; Srem-Sai et al., 2022).

## **Death Competency**

Whilst a range of psychometric scales exist for measuring death anxiety, measures of death competency are restricted to two options – the Self-Competence in Death Work Scale (SC-DWS) (Chan et al., 2015) and the Coping with Death Scale (CDS) (Bugen, 1980; 1981). More recently a short-scale version of the CDS, which in its original form has 30 items and was specifically designed for use with hospice and palliative care professionals, has been developed in response to two things – the fact that studies found that there were problems with items on the original version of the CDS in the form of poor psychometric behaviour of 4 items and low factor loadings for an additional 7 items (Galiana et al., 2017; Schmidt, 2007), and that there are benefits to having brief measures especially when working with HCPs who are often working under time constraints, such as increased response rates (Franke, Rapp & Andzulis, 2013).

The CDS Short version was developed by Galiana et al. (2019) and has been shown to be reliable - Cronbach's alpha (0.854) and Composite Reliability Index (CRI 0.870) (Raykov, 1997) - when used in end-of-life healthcare worker populations and has demonstrated appropriate validity by correlating highly (above 0.90) with the original CDS and moderately (0.33-0.41) with the Professional Quality of Life Scale (Galiana et al., 2019; Stamm, 2011). The CDS short version has been shown to have adequate validity in two different HCP populations (Camarneiro & Gomes, 2015) and hospice volunteers (Robbins, 1991). The scale has also been tested across countries unlike the original Coping with Death Scale (Bugen, 1981; Galiana et al., 2019), and has been found to be a concise yet reliable means of measuring HCPs' death competency (Galiana et al., 2019).

It is easy to administer as it only has 9 items (shown below in Figure 1), making it more suitable to include in a survey compared to the original CDS or the SC-DWS which has 16 items, and covers a range of aspects of coping with death, with items measuring the person's ability to cope with thoughts of their own death, the practicalities of dealing with a death and communicating with others about death and dying. Scoring of the CDS short version is on a seven-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). High scores on the CDS short version indicate that a person is more death competent and therefore better at dealing with death and dying.

Figure 4 Items of the Coping with Death Scale Short version

- 1. I am aware of the full array of emotions which characterise human grief
- 2. I feel prepared to face my dying process
- 3. I can put into words my gut-level feelings about death and dying
- 4. I know who to contact when death occurs
- 5. I will be able to cope with future losses
- 6. I know how to listen to others, including the terminally ill
- 7. I can help someone with their thoughts and feelings about death and dying
- 8. I would be able to talk to a friend or family member about their death
- 9. I can lessen the anxiety of those around me when the topic is death and dying

#### 2.5.3 Sampling Strategy

#### Participants

Participants were all over 18 years old and working in the UK as either a doctor, nurse, or EoL doula (or a combination of these roles). The inclusion of these three specific roles allowed for comparison between traditional (doctors and nurses) and non-traditional (EoL doulas) roles. Full inclusion criteria were as follows: over 18, working in the UK as a doctor, nurse or EoL doula, working in a hospital setting. Only participants working in the UK could take part in the survey as comparing professional roles and the hospital environments across different cultures would have introduced extraneous variables. For example, attitudes to death and dying vary across the world in part influenced by cultural traditions, beliefs, and religions, and this could have resulted in differences in death competency scores. Exclusion criteria were as follows: under age 18, not working in a hospital setting, not working in the UK. Participants were required to have been present at a human death in either a personal or professional capacity, as the survey was based on their appraisal of at least one event.

#### Participant Recruitment

Recruitment was originally planned to be via hospital research departments, and permissions to do this were being sought at the beginning of the Covid-19 pandemic. Due to subsequent pressures on hospitals and prioritisation of research to help

support the effort to manage and overcome the demands of the pandemic, the recruitment strategy had to be re-designed. Therefore, the strategy was changed to include social media-based recruitment.

The wider context of the pandemic at the time of the survey meant that the researcher anticipated that qualitative responses on the survey may have been very brief, and therefore potential over-recruitment was planned to account for this. The nature of data collection, in the form of an online survey, also necessitated the large sample for the qualitative data collection as this was tied to the quantitative sample recruitment as qualitative and quantitative data were collected in tandem. Previous online mixed methods survey studies using template analysis, which is able to comfortably cope with a wide range of sample sizes (Brooks & King, 2014), have reported sample sizes of over 650 (Snijders et al., 2022) suggesting that even very high levels of over-recruitment would not cause issues at the analysis stage.

A combination of convenience and snowball sampling was used to recruit participants. Invitations to participate were shared on the social media platforms Twitter, Facebook, and LinkedIn. Within these platforms invitations were also shared within two relevant Facebook groups - 'End of Life Doulas' and 'Palliative & End of Life Care Educators'. All participants were therefore volunteers.

## 2.5.4 Pilot Study

Once ethical approval was granted for the study, to highlight any possible issues with data collection methodology the online survey was first run with a pilot group of 8 people, made up of colleagues and contacts of the researcher who matched the required participant characteristics (were working in the UK as a doctor, nurse or EoL doula). Each member of the pilot group (2 doctors, 2 nurses and 4 EoL doulas) completed the survey and then provided feedback to the researcher on their experience of completing the survey. Feedback was generally positive, for example that the survey did take around the estimated time (approx. 20-40 minutes), that the questions and instructions were clear, and that they did not experience negative emotional reactions in response to answering the questions. There was feedback that there was repetition in the scale measures however this was unavoidable as this was the nature of the validated scales used.

Two changes were made to the survey in response to feedback from the pilot participants. First, the standardised instructions for the SAM scale were changed from "This questionnaire is concerned with your thoughts about various aspects of the situation identified previously. There are no right or wrong answers. Please respond according to how you view this situation right NOW" to "This questionnaire concerns your thoughts about your first/most memorable experience of being present at a human death – please hold this event in mind whilst completing the following questions. There are no right or wrong answers. Please respond according to how you view this situation right now", as pilot participants felt that 'various aspects of the situation' made it unclear what they were being asked to think about, and that the capitalisation and wording of NOW was off-putting. Second, one of the open-ended survey questions, "Has how you deal with patient deaths changed as a result of the Covid-19 pandemic? If yes, please tell us how'" was removed as this was judged to be both too broad and providing little value in terms of answering the research questions.

Once changes had been made the pilot study participants re-completed the questionnaire and provided further feedback until the consensus amongst the participants was that the survey wording was clear and there were no further issues.

### 2.5.5 Procedure

Data was collected between February and October 2021. All participants completed a web-based survey which was created using the Qualtrics programme and accessed via a link embedded in the invitation post that was posted on social media. This included a demographic section which collected data on the participants role, age, gender, ethnicity, training, and time in current role. The survey then asked about any changes to the person's role because of the Covid-19 pandemic, how often they are generally present at a patient death and how often they engage in advance planning with patients. They were then asked to recall their first experience of being present at a human death and describe this, they then completed the SAM about this experience. They were then asked to repeat this process for their most memorable patient death and to then imagine the next time they may be present at a patient death and to complete the SAM for this imagined future event. Participants were then asked to

describe their goals in the situations of their first experience of a human death. Finally, at the end of the survey they completed the CDS short version.

# 2.6 Ethical Issues

## 2.6.1 Overview

This research followed and complied with the BPS Code of Ethics (British Psychological Society, 2014), as detailed below, and involved additional considerations due to the particularly sensitive nature of the research topic.

# 2.6.2 Protection of Participants

Participants were asked to reflect on and describe their own experiences of death and dying and recall memories of death events they had been present at. As the topic of death and dying is a sensitive subject and one which had the potential to cause distress, the researcher was prepared to direct participants to suitably qualified professionals and/or services if they required support following participation or if they asked for advice. Participants working in the NHS were provided with contact details for their named NHS trust staff therapy service, along with details of Cruse Bereavement Care national helpline. Justification for this potential risk of distress to participants was that all participants encounter death as part of their professional role and the researcher is trained in supporting people to share experiences of death and dying. In addition, previous research suggests that participants' emotional reactions are not necessarily detrimental to participants, nor to the quality of data collected (Cain, 2012). Also in a more general sense, it would limit the reach of social research if we were to avoid collecting data on topics which may be emotional for participants to consider (Kleinman & Copp, 1993).

# 2.6.2 Consent

Fully informed consent was gained from participants using a standardised consent form (Appendix C). Participants gave consent after reading the participant information sheet which detailed the aims of the study, what participation in the study involved, what participants were being asked to consent to and how their data would be handled and used (Appendix B). Participants were presented with a participant information sheet prior to the consent form and were asked to confirm that they had read and understood this. Participants were asked to provide consent for the researcher to publish their data in the form of anonymised quotes and nonidentifiable information relating to their role. The consent form also reminded participants of the sensitive nature of the survey questions, the possibility of this causing them an emotional reaction, and of their right to withdraw.

# 2.6.3 Deception

Participants were fully informed throughout the study and were not deceived at any point.

# 2.6.4 Confidentiality

All participants were anonymous. At the beginning of the survey participants generated a unique participant code which they could quote if they wished to withdraw from the study. Participants were informed that any identifiable information contained within participant quotes from free text responses would be removed or altered in any presentation of findings to ensure that anonymity is maintained, and that no identifying data, including consent forms, would be available outside of the PhD supervisory team.

# 2.6.4 GDPR

Data Protection Act (Data Protection Act, 2018) rules were complied with throughout the study. Only data which was necessary to meet the aims of the study were collected. Data was stored electronically on encrypted drives (hard drives and memory sticks) and within password protected documents. Participants were informed that data would be stored by the researcher for the duration of their study and by the University of Derby for a minimum of 6 years as per university guidelines.

## 2.6.5 Right to Withdraw

Participants were informed of their right to withdraw from the investigation. Methods of withdrawal were explained to participants via the debrief form presented to them at the end of the online survey. This included the researcher's and their supervisor's contact details. Participants were informed that they could withdraw their data from the study for up to two weeks following their participation by emailing the researcher with a request to withdraw, and that should they choose to do so there would be no negative consequences for them.

### 2.6.6 Debriefing

A standardised debrief form was presented to all participants following completion of the online survey, which detailed the purpose of the study and provided details of participants' right to withdraw and methods of doing so should they wish (Appendix E). The debrief also included the signposting information to support services mentioned above.

### 2.7 Methods of Analysis

### 2.7.1 Quantitative Analytic Strategy

Quantitative data collected via the online survey was analysed using IBM SPSS Statistics Version 27 in line with the research objectives.

The original qualitative analytic strategy planned to explore subtle differences in death event appraisal between recollections of first death experience, most memorable patient death experience and future patient death experience within individual participants, between traditional and non-traditional professional roles and in relation to levels of experience. Due to changes in the planned recruitment strategy as a result of the Covid-19 pandemic and slower, and lower participant recruitment than originally calculated the quantitative analysis was revised to consider only one time point in order to preserve statistical power.

In addition, the decision was made to exclude the data relating to mood as measured by the POMS as the number of participants was insufficient to support the number of predictor variables originally planned in the identified model. This means the model tested in the analysis focuses on appraisal processes as described by the SAM, which is consistent with the main tenets of the transactional model of stress described by (Lazarus & Folkman, 1984) but it does not consider the role of emotions related to those appraisals. Considering the research aims and previous literature the decision was made to focus on the relationship between first death event appraisal and death competency, and differences within these according to professional role and experience, as this should provide the greatest insight into the appraisal processes that bolster death competency (and are therefore most protective against the development of death anxiety) in practice. Before the main analysis was conducted a simple t-test was conducted to explore differences in appraisal between first and most memorable death events to check whether these events were appraised in different ways and no overall difference was found. The main analysis aimed to test the relationship between death competency and appraisal of participants first experience of a death event, using the SAM subscales as predictor variables, with professional role (traditional vs non-traditional) as a moderator in the multiple regression. Further follow-up tests explored differences in appraisal and death competency by professional role and level of experience.

#### 2.7.2 Qualitative Analysis Strategy: Template Analysis

Template analysis is a qualitative data thematic technique which employs a deductive, rather than inductive, approach (King 2012) which allows for hierarchical coding – beginning with broad themes before narrowing. It is a good fit for this mixed methods study as template themes can be informed by the theory which underpins the quantitative data collection methods (psychometric scales). Template analysis also lends itself to larger data sets in comparison to Interpretative Phenomenological Analysis (IPA) (King, 2012) which again makes it a better choice for this research. Template analysis has been used effectively in several study areas relevant to this PhD such as carers experience of palliative care services (Goldschmidt et al., 2006; King et al 2003), midwifery (Buchanan et al., 2021), dementia care (Anderson-Ingstrup & Ridder, 2020), perinatal bereavement (Silverio et al., 2021) and healthcare workers experiences of the Covid-19 pandemic (Richards et al., 2022).

When conducting template analysis, the researcher begins by identifying a priori themes which are strongly expected to be present in the data based on the underpinning theory. These themes are coded, and then new themes are developed where needed in response to data which does not fit these initial codes, allowing for further development of theory. The process of template analysis can be summarised in seven stages: 1) development of a priori themes 2) familiarisation and refamiliarisation with data through reading and re-reading 3) initial coding – identifying parts of data which fits within a priori themes, and development of new themes for data which does not fit a priori themes 4) production of initial template – a priori codes and newly developed codes condensed into higher-order codes where needed 5) further refinement of template by applying this to full data set, making changes to the template where required 6) use of final template to interpret data 7) quality check at some point during.

As template analysis can be used within a broad range of epistemological positions, the test of its reliability is not on the reliability of coding but on the quality of the researcher's reflexivity (King, 2012), which is discussed in detail in Chapter 5: Reflexivity.

### 2.7.3 Reflexivity

Due to the nature of qualitative methods, and therefore mixed methods research, there is opportunity for the researcher's own views, biases, position, and assumptions surrounding a research question to influence the findings of a study. In research such as the present PhD, where a form of thematic analysis is used, which inevitably has an interpretative component, it is not sufficient to rely on the traditional concept of rigour alone, but also to assess the study in terms of 'trustworthiness' (Andrew & Halcomb, 2009). This in turn means that there is no single way of judging validity and reliability of a mixed methods study, but rather that to maximise the likelihood of methodological rigour requires critical self-awareness on the part of the researcher to ensure that the nature of the data being 'mixed' and therefore what validation approaches are appropriate – in terms of the data collected, the analysis used and the theoretical assumptions underlying the study. Therefore, for qualitative research to be of high quality is it vital that the researcher(s) are aware of their biases and assumptions and reflect on these throughout the process of the study.

This is known as reflexivity, which can be described as both a tool and a process that facilitates critical self-reflection by the researcher. Reflexivity is not only an essential ingredient in trustworthy qualitative research (Johnson, Adkins & Chauvin, 2020) but also a beneficial and potentially transformational exercise fostering increased self-awareness and enlightenment for the researcher themselves (Narayanasamy, 2015;

Probst, 2015). Reflexivity is equally valuable for qualitative, quantitative, and mixed methods studies (Peddle, 2021) as in all these methodologies there is interaction between the researcher and participants, resulting in a need to understand the impact these have on each other (Darawsheh, 2014; Peddle, 2021) and how this may subsequently affect the data collected and analysis undertaken (Peddle, 2021).

Reflexivity is both a means of improving rigor and trustworthiness of research and a method of producing insight data regarding the researcher's position in relation to the research topic and objectives. It is therefore included here as a method of analysis complementing the previously described methods and providing a unique perspective from which to interpret findings.

In relation to template analysis used in this research, a common example of bias is being emotionally swayed by reading a participant's story resulting in the researcher attributing a theme to the data that was not present (King, 2012). It is especially important to consider this possibility in the case of this research, which required the researcher to read detailed descriptions of death events which in many cases were highly emotive. The researcher took steps to mitigate this, both for quality of data analysis reasons and for self-care, by a) allowing time between readings to process the information and b) ensuring that coding was not done immediately after initial read-throughs when the information was most 'fresh' and emotive. A further overall mitigation to such bias is that template analysis lends itself to objective analysis as it encourages the researcher to be explicit about the decisions they are making and to centre these in the data (King, 2012).

For template analysis, one of the recommended ways of facilitating reflexivity is for a constructively critical 'expert panel' to review the analysis and 'interrogate' the researcher on their decision making. Meetings between the researcher and their supervisor were held for this purpose during the template analysis process. This is not a way of finding a 'correct' interpretation of results, as qualitative data is always open to being read in different ways, but a means of encouraging the researcher to reflect on their own role in the process and in turn enable the identification of points which may have been overlooked. The researcher also kept a research journal detailing thoughts and decisions throughout the study as a tool to facilitate awareness of biases and therefore allow maximum opportunity to mitigate these.

This is in line with recommended methods of researcher self-care and research transparency which has been specifically recommended for death studies research (Valentine, 2007). Chapter 5: Reflexivity discusses extracts from the researcher's research journal made during the template analysis, for example first impressions after the first reading of the data and reflections on how the researchers own experience of patient death events could have influenced analysis.

A further important consideration in line with APA reporting guidelines for mixed methods studies, is for the researcher to consider how their own background may have influenced the research process and findings. This has also been particularly recommended in the field of death studies to enable "less filtering out of the researcher self" and more transparency (Valentine, 2007) with previous researchers in this area arguing for "the emotional to be taken out of the margins" of death studies research (Visser, 2016). In the context of this research, this approach was a) 'built into' the methods used, for example the previously mentioned reflexivity during template analysis, b) aligned with my own approach to development as a researcher using a journal to document and explore my feelings whilst completing this research and c) evidenced in my thesis writing as I aimed to 'write myself in' throughout.

This section has discussed reflexivity in relation to the methodology of this PhD, a more in-depth exploration of the interaction between the researcher's roles as a PhD student studying EoL doulas and as a practising EoL doula herself is provided in Chapter 5: Reflexivity.

### 2.7.4 Integration of Analysis: Triangulation

A key decision regarding the analysis for this research was deciding at which point data would be integrated as part of the mixed methods design. It is recommended that this process is done at a stage before the discussion of results, that it is instead at the heart of the analysis as this allows the qualitative and quantitative data to truly inform the analysis of one another (Andrew & Halcomb, 2006). It is important to not only report the rationale for mixed methods in this research, but also how such integration was achieved (Mertens, 2011) both within the cross-sectional survey study and the wider PhD.

Firstly, findings from the systematic review and meta-synthesis – in the form of key identified themes – informed the a priori codes used in the template analysis within the survey study.

Secondly, the analysis of the qualitative and quantitative data in the mixed methods survey were treated as 'concurrent and equal'. This means that neither qualitative nor quantitative evidence were viewed as having more 'weight' - neither qualitative nor quantitative were taken to be dominant over the other, and aspects of each analysis were informed by the other. For example, the *a priori* codes used in the template analysis of the qualitative data were informed by the subscales of the psychometric scales used in the collection of the quantitative data. Conversely, the most prominent themes identified using the template analysis informed the quantitative analysis.

Thirdly, unique insight data generated through researcher reflexivity (discussed in Chapter 5: Reflexivity) was used to inform interpretation of overall PhD findings presented in Chapter 6: Discussion.

These three methods of analysis come together through the process of triangulation (Mertens & Hesse-Biber, 2012) introduced earlier in this chapter, in order to form a comprehensive understanding of death competency. This approach is appropriate for this PhD as answering the study research questions requires qualitative data demonstrating how HCPs cope with patient death events, quantitative and qualitative data detailing participants individual experiences of patient death events, with none of these individual components being sufficient to answer the questions alone.

### 2.8 Methodology Challenges and Limitations

### Methodological Limitations

The use of convenience sampling resulting in all participants being volunteers means that there is a chance that those who choose to take part in the study are more likely to have high levels of death competency. As we know that low death competency can cause people to avoid the topic of death and dying (Braun, Gordon & Uziely, 2010; Clare, Elander & Baraniak, 2020; Eggerman & Dustin, 1986), those with low death competency may have avoided taking part in the survey. As the mixed methods survey relied on self-report measures of death competency and appraisal, it is important to acknowledge that recall and reporting bias may affect results (Coughlin, 1990; Raphael, 1987). This is particularly relevant to this research as it specifically asked participants to recall past events which occurred at the beginning of their career. This limitation is somewhat mitigated by the fact that participants were asked to recall their first and most memorable death events, which were likely to have been emotional events for them, meaning that recall of visual details of the event is likely to have been more accurate (Cooper, Kensinger & Ritchey, 2019; Xie & Zhang, 2017).

As with any online survey there was the potential for dropout during survey completion to be an issue, as research suggests that around 10% of participants can be expected to drop out of an online survey almost immediately (Hoerger, 2010) and expected completion rates for online surveys ranging widely between 34-87% (Cook, Heath & Thompson, 2000; Liu & Wronski, 2017) depending on many factors including survey platform, survey length, task difficulty and the presence of a progress bar (Liu & Wronski, 2017).

The wider context of the Covid-19 pandemic, discussed in the introduction to this chapter, affected survey recruitment, as whilst this was ultimately successful, recruitment started slowly and coincided with the start of the pandemic. Completion rates increased after the survey had been open for 3-4 months, and so the decision was made to conduct a single larger survey rather than split this into two separate data collection phases. Despite recruitment being slow, participants provided a great deal of rich and detailed qualitative data.

A number of characteristics of this survey increase the likelihood of drop out, namely the survey is considered to be long (Liu & Wronski, 2017) - taking approximately 20-40 minutes to complete depending on how much the participant chose to write for open-text response sections, the repetitive nature of the psychometric scales – for example participants were required to complete the SAM three times, and the personal nature of some of the questions which ask participants to describe difficult and often traumatic experiences. However, pilot study feedback did not refer to survey length and indeed interested and committed professionals reported being prepared to spend time completing the survey, and participants were advised of survey length as part of the consent process. Surveys containing open-text response boxes have also been shown to have lower completion rates due to the associated cognitive effort required from participants to answer these (Manfreda & Vehovar, 2002) though these are necessary for this research to collect qualitative data on death event appraisal. These questions were deliberately placed later in the survey as this has been shown to reduce the risk of dropout (Ganassali, 2008; Liu & Wronski, 2017). Participants were not recompensed for their time and no incentive was offered to encourage participants to complete the survey, both of which could potentially have reduced completion rates; however, this was judged to be unethical due to the sensitive nature of the questions being asked. The researcher made the decision not to make questions compulsory apart from the initial screening question, and intentionally began the survey with short, multiple choice questions as this has been shown to improve completion rates (Liu & Wronski, 2017).

#### 2.9 Chapter Summary

This chapter has detailed the methodology, method, and procedures of this PhD, which can be summarised as a systematic review and meta-synthesis, a mixed methods study using a cross-sectional within-subjects online survey and reflexivity. It has discussed the rationale and use of a mixed methods design, the psychometric scales used, participant sampling and recruitment, ethical considerations, and methods of analysis. This chapter also evidences the reflexive process used throughout the course of this PhD, in particular the importance of the researcher's awareness, critical analysis of and reflection on her role as both an 'insider' and 'outsider' in this field. This will be revisited in detail in Chapter 5: Reflexivity. Having given an overview of the methods of data generation used in this PhD, subsequent chapters will report the findings of a systematic literature review and meta-synthesis focusing on HCPs' reactions and coping responses to early career patient death events, and a mixed methods exploration of the role of patient death event appraisal in death competency development.

# CHAPTER 4: A MIXED METHODS EXPLORATION OF THE ROLE OF PATIENT DEATH EVENT APPRAISAL IN DEATH COMPETENCY DEVELOPMENT

Content warning: some content in this chapter may be distressing, as it contains quotes from participants about deaths they have witnessed. Some of this pertains to content including the death of a child and descriptions of traumatic deaths.

# 4.1 Introduction

This chapter presents the findings of this mixed methods study along with a focused discussion positioning these findings within the context of the wider thesis, detailing practical applications of the findings and offers recommendations in relation to practice and future research.

# 4.1.1 Background: Context for Study

Previous literature reviews have reported that a minority of existing studies exploring HCPs' experiences of patient death focus on patient death itself, with the majority having a wider scope to include HCPs' experiences of providing end of life care (Schulz-Quach, 2018). The findings of the systematic literature review and meta-synthesis presented in Chapter 2, provide further support for this, and emphasise the need for research to focus on HCPs' experiences of patient death events specifically. The need for this focus is extended by the wider context of present-day end of life care in the UK and other Western countries. It has been well-documented that there is little support and training for HCPs working in traditional roles, such as doctors and nurses, when it comes to death and dying (Walker at al., 2016), leading to calls for additional training from junior doctors themselves (Bowden et al, 2013; Centofanti et al., 2016; Charlton & Smith, 2000; Gibbins, McCoubrie & Forbes, 2011; Linane et al., 2019; Price & Schofield, 2015; Redman et al., 2017).

This need has been thrown into sharper focus in recent years due to a combination of factors resulting in increased pressures on HCPs working in hospital environments. Firstly, the recent, and ongoing, global Covid-19 pandemic exacerbated pre-existing issues due to severe staff shortages preventing safe delivery of patient care (Beech et al., 2019; Nyashanu, Pfende & Ekpenyong, 2020) which continue to date. At the time of writing this chapter, junior doctors in England,

Wales and Northern Ireland were currently on strike due to an ongoing dispute over pay, record numbers of staff vacancies and subsequent impacts on patient safety (Jones, 2023). This also had a significant negative impact on HCPs' wellbeing, with qualitative studies exploring the experience of health and social care professionals during the Covid-19 pandemic reporting that participants experienced increased fear and anxiety specifically in relation to the untreatable nature of Covid-19 and the deaths of fellow healthcare workers (Nyashanu, Pfende & Ekpenyong, 2020).

Secondly, our aging population in the UK means that deaths and palliative care needs are predicted to increase rapidly over the next 20 years (Etkind et al., 2017; Finucane et al, 2019) with a recent *Better End of Life Research* report concluding that improved end of life care resourcing is urgently needed in the UK (Marie Curie, 2022). This wider context has emphasised the need for research to explore how HCPs cope with patient deaths and to identify effective ways of support them in doing so.

### 4.1.2 Death Competency

Avoidance of conversations regarding death and dying by health workers in hospital settings has been identified as a significant barrier to provision of end-of-life care (Reid et al., 2013). This avoidance and distancing from dying patients has been theorised to be a coping strategy for health workers' low level of death competency (Kelly, 1955; Neimeyer, 2015). Death competency refers to "a range of human skills and capabilities in dealing with death, as well as our beliefs and attitudes about these capabilities" (Robbins, 1994). Death competency is a highly relevant attribute for individuals for whom dealing with death is part of their professional role, to the extent that it has been argued that death competency development is an ethical issue due to the demonstrated negative effects of low death competency - burnout, compassion fatigue and poor quality patient-practitioner communication (Chan, Tin & Wong, 2015). Identifying predictors of death competency could highlight areas where training and support are required, and where intervention would be most beneficial. By identifying what factors facilitate and promote the development of death competency, we may be able to provide more focused support to minimise the negative effects of death anxiety on HCPs themselves, such as burnout, and on

patients' quality of care, in the form of avoidance of discussion regarding the patient's wishes and prognosis.

### 4.1.3 Death Event Appraisal

HCPs' response to the same patient death varies between individuals, as we all experience different responses to the same event due to our different evaluations and interpretations of what happened (Hwang, 2006). As such, viewing patient deaths as 'death events' can give us a framework to explore HCPs' individual responses and subsequent outcomes, for example development of death competency or increased death anxiety. Recent studies have utilised event appraisal theories to study HCPs' emotional responses to death as an event (Kessler et al., 2012).

As reported in Chapter 2: Literature Review and Meta-Synthesis, the same patient death event can cause contrasting reactions and coping responses in HCPs with one of the key factors being individual appraisal of the event for example whether the person appraises the event as a learning opportunity (challenge appraisal) or a failure. Appraisal is therefore a good concept to measure in this study as it allows us to explore further how such individual evaluation of a patient death event may influence death competency.

As presented in Chapter 1: Introduction and Background, theories of event appraisal built on the work of Richard Lazarus and colleagues who conducted extensive research into the psychological theory of stress and coping (Folkman et al., 1986; Lazarus & Folkman, 1984). Cognitive appraisal refers to "the process of evaluating or categorising the personal significance of events" (Peacock & Wong, 1990), and involves two processes – cognitive appraisal of an event and subsequent coping – and explains how these mediate interactions between a person and their environment, as well as influencing the short and long-term outcomes of the event (Folkman et al., 1986; Lazarus & Folkman, 1984). Cognitive appraisal is split into primary and secondary appraisal, with primary appraisal involving the individual assessing whether the event poses a risk of harm or benefit to themselves, to a loved one, to their own self-esteem or to their goals. Secondary appraisal follows this and refers to the individual evaluating whether they can influence the outcome of the

event by either preventing harm or maximising benefit, and whether they have the tools to cope with the situation (Folkman et al., 1986; Lazarus & Folkman., 1984).

The Stress Appraisal Measure (SAM) is a self-report measure based on this theory of cognitive appraisal, developed by Peacock & Wong (1990). The SAM subscales measures six dimensions of appraisal - three primary appraisal measures: centrality, threat, and challenge, and three secondary appraisal measures: controllable-by-self, controllable-by-others and uncontrollable by anyone, as well as overall perceived stressfulness of the event.

Centrality appraisals are concerned with whether the individual views the event as central to their personal wellbeing. It has been shown to be particularly closely associated with the overall stressfulness of an event (Lazarus & Folkman, 1984; Peacock & Wong, 1990) and previous research has found that centrality appraisals are linked to post traumatic stress disorder (PTSD) symptoms (Barton, Boals & Knowles, 2013; Berntsen & Rubin, 2006).

Threat appraisal refers to whether an individual perceives an event as dangerous to themselves and/or those important to them. Appraising an event as a danger leads to anxiety, and threat appraisals are therefore most relevant when considering future events that have not yet occurred (Peacock & Wong, 1990).

The challenge subscale is particularly relevant to this study as the concept, which refers to the viewpoint that change and situations which draw on coping resources are opportunities for growth and learning rather than threats, has been refined based on application to 'high reliability occupations' such as healthcare roles, characterised by high demands and high cost should failure occur (Carpenter, 2016). Challenge appraisals are known to reduce the likelihood that a person will view an event as a threat to their wellbeing, in turn resulting in better event outcomes (Skinner and Brewer, 2002).

The three secondary appraisal subscales, all measures of perceived controllability, are related to the concept of locus of control (Rotter, 1966), which refers to the fact that individuals attribute the cause or control of events either to themselves (internal locus of control) or the external environment and/or others (external locus of control).

### 4.1.4 Early Career and Most Memorable Patient Deaths

It has been repeatedly recognised in recent decades that nurses' first experience of a patient's death can have a significant impact on their future practice by leading to feelings of helplessness, defensiveness, and distress, resulting in coping strategies such as distancing, emotional suppression, and avoidance (Anderson, Kent & Owens, 2015; Gerow et al., 2010). Similar findings have been reported for doctors, with evidence from a recent literature review suggesting that patient deaths early in a junior doctor's career are formative and can have lasting negative impacts for many years after the event (Bharmal et al., 2022).

Other studies have focused on HCPs' most memorable experience of patient death. Sometimes these events are also the HCP's first experience of a death, with Rhodes-Kropf et al. (2005) finding that the most memorable patient death was also the first death experienced for at least 66% of medical students in their study. Anderson et al (2015) researched a combination of these events, collecting narratives of nurses' earliest, memorable patient death using semi-structured interviews. Interpretative Phenomenological Analysis (IPA) found seven themes which were organised into features of positive or negative patient death experiences: event significance, emotional challenges, sharing the experience, learning, feeling unprepared, responses to death and finding benefits (Anderson et al., 2015). As far as the researcher is aware, this is the only other study which has used HCPs' narratives of patient deaths to identify key factors within these, however unlike the current study Anderson *et al* did not explore how such factors influence the HCPs' death competency, only what factors made the patient death a positive or negative experience.

### 4.2 Aims and Objectives

This study will address PhD objectives 2-4 and aims to investigate the relationship between death event appraisal and professional role and experience with development of death competency.

# Aim

To explore how HCPs' appraisal of patient death events affect their development of death competency, whether appraisal of such events and death competency differs between traditional and non-traditional healthcare roles and by level of experience, and to identify possible predictors of death competency.

# Objectives

- To conduct a mixed methods exploration of HCPs' narratives of patient death events to investigate their appraisal of such events and their subsequent ability to develop death competency.
- To compare differences in patient death event appraisal according to professional training and identity focussing on traditional and nontraditional healthcare roles specifically doctors, nurses, and end of life doulas.
- 3. To identify potential predictors of death competency development following first experience of a patient death event

### **Research Questions**

This study aims to answer, "how do HCPs' individual appraisals of patient death events affect their death competency development and does this differ by professional role?" and "what aspects of patient death event appraisal predict death competency development?"

### 4.3 Method

# 4.2.1 Design

This study used a mixed methods cross-sectional within-subjects online survey to investigate HCPs' experiences of patient death events. The survey employed both quantitative data collection methods in the form of validated scales - the Coping with Death Scale (CDS) Short Version (Galiana et al., 2019) and Stress Appraisal Measure (SAM) (Peacock & Wong, 1990), and statements requiring Likert scale responses, as well as free text response boxes to collect qualitative data on individual experiences of death events and individuals' appraisal of these. Items

within the SAM are phrased as individual questions referring to the extent to which the person felt or feels the event was, for example, uncontrollable – such as item 3 "Is the outcome of this situation uncontrollable by anyone?". Items of the Coping with Death Scale Short Version are phrased as statements, for example item 5 *"I will be able to cope with future losses"*. Both the SAM and the CDS Short Version require Likert scale responses. The rationale for the use of these scales is detailed in Chapter 2: Methodology.

To highlight any possible issues with the design of the online survey, this was piloted with a group of 8 people, made up of colleagues and contacts of the researcher who matched the required participant characteristics (were working in the UK as a doctor, nurse, or EoL doula). Each member of the pilot group (2 doctors, 2 nurses and 4 EoL doulas) completed the survey and then provided feedback to the researcher. A more detailed account of the survey piloting process is reported in Chapter 2: Methodology.

### 4.2.2 Participants

A combination of convenience and snowball sampling was used to recruit participants, with purposive sampling used to target participants likely to yield the most information-rich cases, such as palliative care hospital settings. Participant invitations to take part in the study were distributed on social media (Facebook and Twitter). All participants were therefore volunteers.

Participant inclusion criteria were being over 18 years old, currently working as a doctor or nurse in a hospital setting (NHS or private service) or as an EoL doula, working in the UK, and having been present at a death event in either a personal or professional capacity. Participant exclusion criteria were being under 18, not working in a hospital setting as a doctor or nurse or as an EoL doula, or not working in the UK.

283 participants took part in the survey, with 199 starting the survey but dropping out part way through, and 84 completing it. 156 participants completed the qualitative data collection free-text boxes describing their first experience of a death, and 114 participants completed free-text boxes describing their most memorable patient death. Demographic statistics regarding participant gender, ethnicity, age, role, and time in role are presented in table 11 below.

Table 11 Participant Demographics

| Factor                    | Ν   | Percentage |
|---------------------------|-----|------------|
| Gender                    |     |            |
| Male frequency            | 20  | 7.1        |
| Female frequency          | 259 | 91.5       |
| Prefer not to say         | 2   | 0.7        |
| Self-describe             | 2   | 0.7        |
| Ethnicity                 |     |            |
| English, Welsh            | 235 | 83         |
| Irish                     | 11  | 3.9        |
| Other white               | 15  | 5.3        |
| White and black Caribbean | 4   | 1.4        |
| White and black African   | 1   | 0.4        |
| White and Asian           | 1   | 0.4        |
| Other mixed               | 2   | 0.7        |
| Indian                    | 4   | 1.4        |
| Prefer not to say         | 4   | 1.4        |
| Chinese                   | 2   | 0.7        |
| Pakistani                 | 3   | 1.1        |
| Other Asian               | 1   | 0.4        |
| Age                       |     |            |
| 18-25                     | 4   | 1.4        |
| 26-35                     | 54  | 19.1       |
| 36-45                     | 69  | 24.4       |
| 46-55                     | 87  | 30.7       |
|                           |     |            |

| 56-65             | 53  | 18.7 |
|-------------------|-----|------|
| 66+               | 12  | 4.2  |
| Prefer not to say | 4   | 1.4  |
| Role              |     |      |
| Doctor            | 48  | 16.1 |
| Nurse             | 191 | 63.9 |
| EoL Doula         | 36  | 12   |
| Doctor and doula  | 1   | 0.3  |
| Nurse and doula   | 11  | 3.7  |
| Time in role      |     |      |
| 1-5 years         | 98  | 45.4 |
| 5-10 years        | 51  | 23.6 |
| 10-20 years       | 28  | 13   |
| Over 20 years     | 16  | 7.4  |
| Less than a year  | 23  | 10.6 |
|                   |     |      |

### 4.2.2 Procedure

Data was collected between February and October 2021. After being recruited to the study via social media, participants were fully informed via an on-screen participant information sheet and consent was taken as part of the online survey. Participants were allowed up to two weeks to complete the survey, permitting them to pause and return to complete the survey without having to restart it.

The survey began by collecting demographic data relating to the participants role, age, gender, ethnicity, training, and time in current role. The Stress Appraisal Measure (SAM) (Peacock & Wong, 1990) was used to collect quantitative data related to HCPs' appraisal of three death events: their first experience of being present at a human death, their most memorable patient death, and a future imagined patient death event. The Coping with Death Scale Short Version (Galiana et al., 2019) was used to measure death competency.

Qualitative data was collected from two open ended questions in the online survey, each allowing the participant to write up to 500 words in response. Two main pieces of data from two survey questions - *How would you describe your first experience of being present at a human death?* and *how would you describe your most memorable patient death?* were collected from each participant.

Once participants had completed the survey, they were presented with an on-screen debriefing sheet which they also had the option of downloading. This debrief also invited participants to a follow-up interview study which at this point of the PhD was planned – subsequent changes to the original plan due to the Covid-19 pandemic are discussed in Chapter 2: Methodology.

# 4.2.3 Ethical Issues

This study followed and complied with the BPS Code of Ethics (British Psychological Society, 2014) and involved additional considerations due to the particularly sensitive nature of the research topic. Ethical approval for this study was granted on 17/09/2020, ethics number: ETH2021-3110. Evidence of ethical approval is provided as Appendix A.

Full details regarding the design, piloting and ethical considerations of this study are discussed in Chapter 2: Methodology.

### 4.2.4 Methodology: Mixed Methods

As detailed in Chapter 2: Methodology, mixed methods methodology is broadly split into four types - triangulation, exploratory, explanatory, and embedded design (Cresswell & Clark, 2007). Triangulation was judged to be the most appropriate approach for this study, as qualitative and quantitative data were collected simultaneously. Triangulation uses qualitative and quantitative methods to generate complimentary yet different data on the same topic, which is then integrated to inform interpretation and the generation of new knowledge (Cresswell & Clark, 2007).

In this study, both template analysis and quantitative data analysis were used to analyse data from the mixed methods survey. The qualitative data informed quantitative data analysis as the identified themes from the template analysis informed which variables were included in correlational analyses.

In the presentation of findings in this chapter, qualitative data analysis and results will be reported first, followed by quantitative data analysis and results which serve to support the findings of the qualitative analysis.

# 4.4 Qualitative Data Analysis

### 4.4.1 Template Analysis

Template analysis was used to analyse qualitative data which, as detailed in the methodology chapter of this thesis, is well suited to handling a wide range of data set sizes (Brooks, et al., 2014) making it a good fit for this analysis. As described in the previous chapter, template analysis is a deductive form of thematic analysis, which involves beginning with a priori codes, in this case these were derived from the subscales of the SAM and literature review findings, and additional codes were developed as the analysis was conducted. The following section of this chapter described this process in detail.

### 4.4.2 Preliminary Coding and Development of Initial Template

All data collection was completed before analysis began. Step one in the analysis process involved pulling all qualitative data into a text file, reading, and re-reading this for the researcher to fully familiarise herself with the content. As the data was collected via open-text response boxes as part of a mixed methods survey, the size of the data set meant that it was feasible to read through the full data-set multiple times over a relatively short period of time. This was done repeatedly over an initial two-week period, to reduce the risk of bias from reading in one sitting when the researchers emotional state at the time of reading could influence what is most salient in the reading of the data.

A priori codes were developed from existing literature and concurrent quantitative data analysis. A priori themes are those which are identified in advance of the data coding process, based on assumptions made by the researcher as to what may be found and what should be focused on in the data using their knowledge from the research area. For example, it would be appropriate to develop a priori themes based on factors which existing research has shown are relevant and any other wellestablished theories in the area. A priori themes should never be 'set in stone' and should always be open to being changed or removed if they are not shown to be relevant, useful, or appropriate (King, 2012). It is recommended that a priori themes are kept to a minimum to avoid them steering the analysis away from new discovery of themes by restricting the researcher to only their assumptions (King, 2012). These initial a priori codes can be seen in Figure 5 below. For this study, priority areas of focus were drawn from the systematic review of background literature and analysis of quantitative data, as part of the mixed methods triangulation process described in the previous methodology chapter.

As the SAM authors recommend that the subscales challenge and threat are particularly applicable to past event appraisal (which these two survey questions were exploring), these were included as initial a priori codes. A further a priori code, 'death as failure' was taken from the background literature detailed in Chapter 1: Introduction and Background, and findings of the literature review and metasynthesis presented in Chapter 2: Literature Review and Meta-Synthesis.

| A Priori Code                    | Source                     |
|----------------------------------|----------------------------|
| Challenge (learning opportunity) | SAM subscale               |
| Threat                           | SAM subscale               |
| Controllability                  | SAM subscale               |
| Centrality                       | SAM subscale               |
| Death as failure                 | Study 1: Literature review |

### 4.4 Data Analysis

### 4.4.1 Developing and Applying the Template

These a priori themes formed the initial coding template. In template analysis an initial coding template can be applied to a subsection of the dataset to allow for more manageable analysis however this can result in the researcher's ability to approach

the rest of the dataset with an open mind being restricted (King, 2012). In this study due to the manageable size of the data set it was possible to apply this initial coding template to all the data therefore removing this possible risk of bias. Parallel coding was used to mark the same sections of text with multiple codes. It is usual for the template to be applied with required revisions noted and then a new template constructed rather than changing the template after each new piece of data analysed (King, 2012). Therefore, for this study once the template had been applied to the whole dataset the number of times each theme was coded was counted and any a priori themes which did not 'fit' the data and were therefore redundant were removed. Identified new themes were also inserted into the template, and the process repeated until coding was no longer resulting in distinctly different new themes. It is recommended that this process continues until all data which is of clear relevance to the study's research question is coded (King, 2012) – for this study this was done over several weeks until the researcher felt this point had been reached.

Independent scrutiny of analysis during the process of template analysis is advised to maximise quality of data analysis and can be utilised at various stages of the research process (King, 2012). In this study, this was done when analysis was being interpreted for reporting, in the form of regular meetings with a second person familiar with the process of template analysis (AB) who acted as an 'expert panel' (King, 2012) to facilitate interrogation of analytical decisions.

The researcher looked at patterns across the data set and identified, condensed, and prioritised those themes giving the most valuable insights in relation to the study's research questions. The researcher then revisited the dataset once final themes had been named, to ensure that these themes were consistent with the overall dataset.

### 4.5 Results

The final template included four main themes and associated subthemes, and one integrative theme – a theme which runs through the dataset and therefore tends to be present throughout all themes and subthemes (Brooks et al., 2015). In line with the research questions for this study, all themes encompass key factors in participants' appraisal of the patient death event, with three focusing on factors

relating to the HCP themselves, and the final theme including patient factors which appear to influence the HCPs' appraisal.

Figure 6 Final Themes and Subthemes

#### **Themes and Subthemes**

Theme 1: Controllability Appraisal 1.1 Uncontrollable 1.2 Controllable

Theme 2: Challenge AppraisalTheme 3: Death as failure – medicalisation and/or overtreatmentTheme 4: A 'Good Death'

Integrative theme 1: Emotional intensity

Theme 4: A 'Good Death' 4.1Patient Preparation 4.2'Completion'

An integrative theme is a theme which is present throughout all other themes, the identified integrative theme in this study is presented first to frame preceding themes within this overarching context.

### Integrative theme A1: Emotional Intensity

All themes were underpinned by the emotions described by participants. Throughout the dataset participants described experiencing intense emotional reactions to both their first and most memorable patient death event. Emotions may result from appraisals of what is happening during an event and occur when an individual evaluates a situation in relation to personal goals, values, and beliefs (Schutz & Pekrun, 2011).

Commonly used descriptors of emotions by participants were 'shocked', 'frightening', 'distressing', 'terrifying', 'upsetting' and 'traumatic'. Such descriptions were equally present across both first experiences of death (FEoD) and most memorable patient death (MMPD):

"I remember feeling astonished and shocked". (Nurse, FEoD)

*"It was dramatic and horrific and evident there was nothing we could do. It was traumatic". (Doctor, MMPD)* 

*"It was extremely distressing to think of the other patients and potentially the family witnessing the process". (Nurse, MMPD)* 

*"It was severe sad as I had nursed with the patient for weeks prior to death". (Nurse, MMPD)* 

"I remember feeling anxious and fear". (Nurse, FEoD)

"Peaceful but terrifying for me! I was a little traumatised seeing my first dead body and found it all quite grotesque". (Nurse, FEoD)

*"It sounds like something from a movie and as a student it shook me to my core". (Nurse, FEoD)* 

"Unnerving, uncomfortable, upset, tearful". (Nurse, FEoD)

*"I remember feeling very sad and I think frightened about what was actually happening and almost frustrated at this being allowed to happen". (Nurse, FEoD)* 

As well as being able to recall emotional responses at the time of a death event, participants commented on how the death event and emotional reaction continued to impact the HCP for a long period of time, even years after the event.

"A patient passed away whilst I was administering a small stat dose of morphine. This had a negative effect on me...I felt that the family would blame me...my anxiety was in overdrive for months. No amount of reassurance...would help". (Nurse, MMPD)

*"Traumatic. I remember it well though it was over 30 years ago". (Nurse, FEoD)* 

"This has stayed with me for over 30 years. I felt so helpless and angry that he had died, particularly in such a traumatic way. I felt I had let him down". (Nurse, MMPD)

"It still haunts me". (Nurse, FEoD)

"Awful! I was a student so to was 20years plus ago and I didn't know what to expect. Nobody had really prepared me! We moved the lady to do last rites and she exhaled from the pressure of the move- that has stayed with me forever. I did not appreciate how quickly it would happen or the impact it would have on me either. On reflection it was a gentle peaceful deathbut that should have been explained to me". (Nurse, FEoD)

Whilst this theme may be expected due to the nature of the events participants were describing, it still provides an important insight into the fact that HCPs in traditional roles are not 'immune' to experiencing powerful negative emotional responses to patient death despite their training and the fact that they may encounter such events regularly as part of their role. Such negative feelings were often associated with the HCP appraising the patient death event as exceeding their coping resources. Whilst some level of discomfort and feelings of inadequacy are to be expected when a HCP is experiencing this situation for the first time, examples in the data suggested that feelings were stronger and more negative than this – that HCPs felt that they were put into situations without being equipped with the skills or knowledge that they needed to cope with the situation and to provide high quality care to the patient.

Whilst most examples of emotional intensity from doctors and nurses in the data were negative, it was notable that the most positive descriptions came from EoL doulas.

"Transformative...felt I went to 'another place' disconnected but deeply immersed at same time...A stillness that told me this was what life is all about...Felt a heightened sense of the universe around me. Wonderment but ordinary at the same time as I realised a death occurs every moment". (End of life doula, FEoD)

*"Peaceful, beautiful, gentle, mysterious, magical, inspiring, relief".* (End of life doula, FEoD)

"Death itself was gentle but fascinating...Room totally connected with each other. Non-religious but very spiritual feeling". (End of life doula, FEoD)

One potential explanation for this is that the training EoL doulas receive is specifically focused on preparing them to deal with the death of someone they are supporting. Whilst this does not prevent them from feeling intense emotion in response to this, it is likely to prepare them to observe the death with curiosity, and to be able to identify any positive aspects of the situation. In relation to the research question, this highlights a significant different in appraisal between traditional healthcare roles (doctors and nurses) and non-traditional healthcare roles (EoL doulas) in this study.

Further to this integrative theme, qualitative data analysis identified 4 themes which will now be presented.

# 4.5.1 Theme 1: Controllability Appraisal

Controllability refers to the extent to which the person believes they can control the situation and is linked to locus of control. This theme encompasses participants appraisals of the patient death in relation to the extent the HCP believes they were able to influence the situation in terms of the experience of death for the patient and those important to the patient, as well as in terms of their own goals in the situation for example if they were trying to prevent the patient dying.

### Subtheme 1: Uncontrollable

There were many examples throughout the data of participants expressing that they felt ill-equipped to deal with the situation that they were in at the time of the patient's death and unable to influence the outcome. As expected, this subtheme was more frequently identified in descriptions of first experiences of patient death, as in the following examples:

*"I felt so awfully ill prepared...I was newly qualified and in charge at night. I didn't understand what was happening or how best to help him. I felt I let him down. Still haunts me". (Nurse, FEoD)* 

"..the patient was alone, without family or staff, just me looking at the drip in my capacity as a student nurse...I look back and am sad about the person dying alone even though they were on a ward. I feel sad that a drip was in situ. I just wasn't comfortable with dealing with death on the first occasion". (Nurse, FEoD)

Sometimes participants appraisals of the situation being uncontrollable were due to external factors such as availability and efficacy of medication:

"The patient was in sudden intense pain which we just couldn't get on top of". (Nurse, MMPD)

"He was unsettled with significant complications regarding symptom control. The medication he was prescribed was insufficient and ineffective despite high doses". (Doctor, MMPD)

Similar descriptions also featured in participants recall of their most memorable patient death event, and were accompanied by feelings of frustration that they were put in a situation they had not been given the support or training to deal with, for example:

"I felt utterly helpless. I feel in ICU we are poorly equipped to tackle death and dying we are trying to preserve life and there is a lack of ICU specific training". (Nurse, MMPD)

This example also demonstrates the influence of professional role on controllability appraisals – this nurse highlights how their goal in this situation is to preserve life leading to a feeling of hopelessness when this was not possible.

### Subtheme 2: Controllable

Conversely, a number of participants stated that they did feel in control of the situation:

*"It felt urgent and created a sense of alarm that I was able to control and take charge of the situation". (Doctor, MMPD)* 

"person dying was without pain and sleeping comfortably...Felt cold to touch with some mottling of skin to extremities, sleeping, I provided 1:1 support. Situation felt under control and calm". (Nurse, FEoD)

Others described situations in which they had taken the lead. This was associated with the person also taking responsibility for the outcome of the death event, which meant that this was often accompanied by a description of how they felt such as pride or self-blame: "I had been one step ahead all the way and all the meds were in place in good time. I had instigated very good communications with the GP Comms Team". (End of life doula, FEoD)

*"I feel very proud that I created a beautiful, gentle safe space for the man and the family. It was a truly beautiful, gentle death". (End of life doula, FEoD)* 

As well as participants feeling that the patient death events were controllable or uncontrollable by themselves, there were also numerous examples of how HCPs shifted their focus during the events from what they could not control to what they could. For example:

"Patient had catastrophic bleed from tumour pressing on his carotid, patient could feel pressure and knew it was going to go. Could only reassure and put pressure on". (Nurse, FEoD)

"The moment of her death was sudden. Her sister was present and started shouting for help. I was with a more experienced doctor and their presence reassured me that the best thing to do was just be with them. We provided a calming presence and her final minutes of life looked peaceful". (Doctor, FEoD)

"Very rewarding. Patient in prolonged disorder of conscious but clearly in pain. No hope of healing. It was in patients best wishes to give end of life care and it was done well. Family well supported and grateful for care received and the outcome. (Nurse, MMPD)

It appears that this shift in focus could have a useful and potentially protective role to play in that it enabled the HCP to be left with an overall positive memory of the event despite the difficult and in some cases traumatic circumstances.

There are further examples of the effect of professional role in this subtheme, with the EoL doulas referring to their aims of facilitating good quality communication and creating a "gentle safe space". These aims contrast with those in the previous uncontrollable subtheme of preserving life. These findings suggest that training for those in traditional healthcare roles (doctors and nurses) may increase the likelihood that these HCPs appraise a patient death as uncontrollable as they are more likely to be aiming to preserve life, whereas those in non-traditional roles (EoL doulas) appear to have more achievable aims making it more likely that they will appraise the situation as being within their control. This tells us that professional role may dictate whether a HCP views a patient death event as being a positive or 'successful' event if it was consistent with their aims and they believe that they were able to influence the event outcome, and therefore that professional role may affect death competency development.

Through the participant examples in this theme, we can see how the integrative theme of emotional intensity is present – with participants describing uncontrollable situations as "sad", "very rewarding" and "utterly helpless".

# 4.5.2 Theme 2: Challenge Appraisal

Challenge, in the context of event appraisal, refers to the viewpoint that situations which require use of coping resources are opportunities for learning and growth rather than threats (Peacock & Wong, 1990). This theme was predominantly present in participants descriptions of their first experience of a death event, perhaps because these events were usually early in the persons' career and so they were likely to be in a situation that was difficult due to their lack of experience but therefore also provided significant learning opportunities.

Some participants described the death event as a learning experience, and it was notable that this appraisal of the event usually accompanied a description of the event which mentioned imperfect care and an acknowledgement of this. These participants appear to have focused on the positives in this situation and reframed the negative aspects of the experience as an opportunity for growth:

"we didn't get everything right, but I think this was a peaceful death from an aggressive cancer and a huge, valuable learning experience". (End of life doula, FEoD)

*"It was distressing for a 20 year old to process, it taught me about stereotyping in action and I vowed never to be like this, I started my mental health nursing a year later". (Nurse, FEoD)* 

For some participants, they looked back on the event with gratitude to their colleagues at the time who maximised the learning potential of the patient death event:

"The nurse encouraged me to stay - he reassured me it would not [be] voyeuristic, but important & educational". (Doctor, FEoD)

"..it was a barbaric resuscitation on a lady in her 80s. Nothing dignified. However the nursing staff afterwards taught me how to lay her out and returned the dignity and compassion that had been lacked in her last moments". (Nurse, FEoD)

"She took her last deep noisy breath and didn't breathe again. I continued holding her hand. The matron showed me how to perform 'last rights'. We picked flowers and put them in her hands". (Nurse, FEoD)

EoL doulas were more likely to describe the learning opportunity as a broader lesson involving personal growth rather than referring to specific skills:

"The dying teach me how to die". (End of life doula, FEoD)

"Sacred and healing for those left behind- enabled them to grow individually & pass on this knowledge to others". (End of life doula, FEoD)

This theme demonstrates how individual HCPs' appraisal of a patient death event as an opportunity for learning and/or personal growth may facilitate them believing that they will be more able to deal with patient deaths in the future – in other words development of death competency. There are also examples within this theme of how professional role may influence this, with EoL doulas tending to view the patient death as a profound, general life lesson, and doctors and nurses focusing on specific professional skills they had gained and could utilise in future similar situations.

The participant examples in this theme again demonstrate the integrative theme of emotional intensity – with descriptions including "distressing", "healing" and "sacred".

#### 4.5.3 Theme 3: Death as failure – medicalisation and/or overtreatment

This subtheme describes how many participants shared negative descriptions of patient death events linked to their belief that the death involved unnecessary and

distressing medical intervention and individual appraisal that the death was a result of failure on their part or that of the medical system:

"My first experience was in a hospital which was nothing like the lovely deaths that there is in the community....They were in a side room...They had an IV pump, noisy mattress, [nasogastric tube], a syringe driver...It was a night shift and the nurse was busy and the patient was in pain". (Nurse, FEoD)

"It was never really talked about...you came out from behind the curtain on an open ward and everything else just carried on the same. A man had died but nothing had changed. It was disorientating and distressing, the normality and mundanity of it as an event in the running of the ward". (Nurse, FEoD)

"Very traumatic and frantic with the patient being lost in the chaotic treatment being performed on them. I did not witness a normal dying process until later in my career and was pleased to see it treated as a natural process rather than a failure of medicine". (Doctor, FEoD)

"The outcome was negative after prolonged resuscitation. The use of a machine to perform mechanical chest compressions made the situation more intense". (Nurse, MMPD)

*"I think we come into Nursing to ' help people feel better' and at 17yrs old I hadn't prepared myself for how I would feel when this did not happen". (Nurse, FEoD)* 

In some cases, participants described how their distress was increased as they believed that this medical intervention could have been prevented:

"This was really traumatic as we'd spent years working with the family trying to get them to agree to a DNACPR but they refused and so the child was brought into resus by paramedics with full CPR ongoing...it was awful". (Doctor, MMPD) "The resuscitation attempt was unsuccessful. The patient was frail and elderly. The death was not peaceful. The patient could have, and would have, died naturally at home, but instead died as a result of a resuscitation attempt in A&E. It was distressing as it could have been prevented by [advance care planning]/discussion of DNACPR". (Doctor, FEoD)

"While expected death and on reflection peaceful, you feel you should do something. Not given the tools in general training to feel like you can be present without the 'doing'". (Doctor, FEoD)

Narratives of patient deaths which fitted this theme were characterised by negative descriptions, regret, and lasting distress. This is consistent with previous research which found that patient deaths which doctors viewed as 'overtreated' were associated with more intense emotions, more internal conflict and were more disturbing (Jackson et al., 2005).

This theme suggests that appraisal of a patient death as a failure is associated with distress and lasting negative emotions for HCPs and that this could therefore be unhelpful for development of death competency. If a HCP appraises a patient death as a failure, particularly a personal failure, this is likely to negatively impact their self-efficacy for dealing with this event in the future. It may be that the use of debriefing to provide an opportunity for the healthcare professional to reframe this, could go some way to countering the negative effects of such appraisal.

Participant quotes in this theme provide strong examples of the integrative theme of emotional intensity – with descriptions including "really traumatic", "distressing", "intense", "disorientating" and "frantic".

### 4.5.4 Theme 4: A 'Good Death'

Whilst themes 1-3 covered HCPs' individual factors in their appraisals of patient deaths, there were also examples in the data of how patient factors influenced HCPs' view of the death event. This theme details how participants appraised the patient death event they experienced as a 'good death', a term used in existing literature to describe a death which is in line with a person's wishes, peaceful, dignified and planned (Cottrell & Duggleby, 2016; Smith, 2000; Steinhauser et al., 2000). Whether

participant viewed the patient death as a 'good death' appeared to be largely due to two factors, presented here as subthemes, firstly the extent to which the patient had prepared for their death, and secondly a sense of 'completion' – of a fitting ending to a life.

# Subtheme 1: Patient Preparation

Participants appeared to describe more positive experiences of patient death when the patient and those important to them had collaborated with HCPs' to prepare for their death, for example in the form of documenting wishes and having conversations with family members about death and dying, which in turn facilitated early referrals, procurement of anticipatory medications, good quality advance care planning and in many cases an end of life which was in line with the person's wishes and preferences:

"Intervention planned carefully with the patient and with great respect and compassion. Trusting relationships built between patient, family and staff. Family had prepared and it enabled us to provide a peaceful, wellmanaged and gentle decline to death". (Nurse, MMPD)

"Well managed – patient was aware in advance that it was going to happen, discussions about what they wanted, where they wanted to be, GP on board, anticipatory meds in place and family well supported. It was 'planned' in that it was known about and best attempts to make what the patient wanted happened. Very holistic". (Nurse, MMPD)

"We carefully planned...kept him and his family informed throughout. We asked what was important to him, what sort of things he enjoyed. At the end...we were all so grateful he had his favourite music playing, pink sponges of whiskey and sisters by his side. I felt emotional but content". (End of life doula, MMPD)

Even in cases where the patient death had been traumatic, this seemed to allow the HCP to focus on the positives and still be left with a feeling that they had achieved a 'good death':

"Very well planned for with emergency health care plan, anticipatory medications in place with patient wishes clearly expressed and a plan for family members. It was traumatic as it was my first experience but this all meant that I felt good overall and the patient was calm and pain-free". (Nurse, MMPD)

As well as positive descriptions of the benefits of preparation, there were also examples of how a lack of preparation left the HCP with a negative and/or traumatic memory of the event:

"she and her husband had prevented HCPs from preparing the children for the death of their mother". (Nurse, MMPD)

*"I now see she was palliative..but we had no DNR in place, she was still under surgeons...I had to make a crash call and resus was unsuccessful. Traumatic and poorly managed". (Nurse, MMPD)* 

### Subtheme 2: 'Completion'

A further patient factor which appeared to positively influence the HCPs' appraisals of the death event they experienced was whether the patient had fostered a sense of 'completion' for example by tying up loose ends, expressing that they felt they had lived a full life and had their wishes and preferences met – meaning that this subtheme is connected to the previous 'preparation' subtheme as a sense of completion often relies on adequate preparation. 'Completion' was represented in descriptions of both events and was in the form of a sense of general life completion for example in the following examples:

"No distress, in his own bed on the street where all his children had been born. It was like a complete circle of life". (Nurse, MMPD)

"A 94 year old...he was not in distress and this was a very natural process...This struck me as the normal process of a tired body, shutting down and finishing its work. He was at home, with his family present and sun streaming through his familiar window". (End of life doula, MMPD)

*"Peaceful, sad, calm, time for important people to say goodbye and talk to her. A life well lived. All family visited and were appreciative". (Doctor, MMPD)* 

'Completion' was not only demonstrated in the cases of elderly and/or palliative patients, but it could also refer to a sense of complete-ness in the moment, for example:

"Nothing more to do, surrounded by loved ones, symptoms controlled, all questions asked and answered, the little things all taken care of. Privacy but also opportunity to call for support. Everyone's' physical, psychological, spiritual and social needs addressed". (Nurse, MMPD)

"all the family, siblings, were able to say their goodbyes, create memories of handprint, footprints, were comforted by their belief system, the child gently slipped away in their parents' arms. A death where you felt that everything that could be done medically was done". (Nurse, MMPD)

The integrative theme of emotional intensity is again demonstrated in this final theme, with participant descriptions including "sad", "traumatic" and "emotional".

In the context of this study's research question, appraisal of the patient death event as a 'good death' is likely to facilitate death competency development as if the HCP believes that they were able to play an active part in the team of people surrounding the patient and the patient themselves to achieve this, they may be more likely to feel that they can deal with this situation again in the future. In terms of professional role, both HCPs in traditional and non-traditional roles can support patients with advance planning, however, EoL doulas may have more time to spend with patients on this aspect of their care. This may mean that EoL doulas are more likely to feel that they influenced the outcome of a 'good death'.

In addition to the detailed, emotive, and rich qualitative data presented in this section, as part of this mixed methods study quantitative data was also collected. The analysis of this data and subsequent results will now be presented.

### 4.6 Quantitative Data Analysis

In this section the term SAM1 is used to refer to participant appraisal scores on their first experience of a death (FEoD).

To answer the research questions "how do HCPs' individual appraisals of patient death events affect their death competency development and does this differ by professional role?" and "what aspects of patient death event appraisal predict death competency development?", the key hypotheses being tested in this section are as follows:

- 1. There will be a significant difference in death event appraisal and death competency by professional role
- 2. There will be a significant impact of experience, measured by years in role, on death competency
- 3. Death event appraisal will significantly predict death competency

# 4.6.1 Data Analysis Strategy

The statistics software IBM SPSS Statistics Version 27 was used for analysis.

An a priori power analysis using the software package GPower (Faul et al., 2007) was conducted to determine minimum sample size required. This indicated the required sample size for detecting a medium effect at a significance criterion of  $\alpha$  = .05 with power at 0.8 was *N* = 160. This calculation was made at the outset of study design, at which point the planned number of predictor variables was 21.

283 participants took part in the survey. Data was cleaned to remove any missing data and incomplete cases were removed. Only complete cases were used for analysis, resulting in a final participant number of 84. There were no outliers in the data and so no outliers were removed.

The SAM - Cronbach's alpha 0.74 to 0.90 (Gan & Anshel, 2006; Gan, Anshel & Kim, 2009; Srem-Sai et al., 2022) and CDS Short version - Cronbach's alpha 0.854 Galiana et al. (2019) were used to collect quantitative appraisal and death competency data.

As this study measured death event appraisal for both first experience of a death and most memorable patient death, it was necessary to establish the relationship between SAM1 and SAM2 scores. Skew and Kurtosis were within the acceptable threshold values of +-1.96. The SAM1 and SAM2 scores of D(109) = 0.083 and D(109) = 0.079 respectively, were not significantly different.

At this point the decision was made to focus multiple regression analysis on participants first experience of a death event (SAM1 scores), as qualitative data demonstrated that for many participants these events were one and the same. As reported above no significant difference was found between SAM1 and SAM2 scores.

### 4.6.3 Descriptive Analyses

### Variable Overview

Means and standard deviations for all continuous variables included in analyses are presented below in Figure 7.

| Variable                      | Mean    | Std. Deviation | Ν  |
|-------------------------------|---------|----------------|----|
| Death Competency              | 29.5357 | 18.66860       | 84 |
| SAM1 Controllable-by-self     | 0.1196  | 3.95543        | 84 |
| SAM1 Threat                   | 0.1470  | 3.35421        | 84 |
| SAM1 Centrality               | 0.1758  | 4.48423        | 84 |
| SAM1 Uncontrollable-by-anyone | 0.0899  | 3.99244        | 84 |
| SAM1 Controllable-by-others   | 0.2713  | 4.26409        | 84 |
| SAM1 Challenge                | 0.2129  | 3.48497        | 84 |
| SAM1 Total Stress             | 0.1314  | 3.47854        | 84 |

Figure 7 Means and Standard Deviations

Included categorical variables were as follows. Professional roles: doctors N = 48; nurses N = 191; end of life doulas N = 36; doctor and end of life doula N = 1; nurse and end of life doula N = 11. Years in role: less than a year N = 23; 1-5 years N = 98; 5-10 years N = 51; 10-20 years N = 28; over 20 years N = 16.

## Parametric Assumptions

For death competency scores, Skew was within the acceptable threshold value of +-1.96, Kurtosis was beyond threshold. As regression is a sufficiently robust analytical method this was deemed unlikely to impact the analysis (Arnau et al., 2013).

All SAM1 variables were within acceptable thresholds for Skew and Kurtosis.

For SAM1 challenge scores, a non-significant Kolmogorov-Smirnov test indicated that scores follow a normal distribution D(148) = 0.065, p = 0.200, therefore assumptions for parametric testing were met.

For SAM1 controllable-by-self scores, a significant Kolmogorov-Smirnov test indicated that scores do not follow a normal distribution D(147) = 0.093, p = 0.003 therefore assumptions for parametric testing were not met.

For number of years in role, Skew and Kurtosis were within acceptable thresholds, a significant Kolmogorov-Smirnov test indicated that scores do not follow a normal distribution D(216) = 0.255, p = 0.000 therefore assumptions for parametric testing were not met.

These results of parametric assumption testing dictated the analysis conducted in the following sections to test the study hypotheses.

# 4.6.4 Differences in Death Competency and Appraisal Between Roles and by Experience

To explore differences in patient death event appraisal and death competency by professional role, death competency scores between doctors, nurses and EoL doulas were compared. A Kruskal-Wallis test was run to explore whether death competency differed between doctors, nurses and EoL doulas. There was a significant effect for professional role, with EoL doulas having significantly higher death competency scores than nurses and doctors H(2) = 16.27, p = .000. The effect size, eta squared ( $\eta^2$ ) was 0.20, indicating a large effect (Tomczak & Tomczak, 2014).

To test the hypothesis that there would be a significant impact of experience, measured by years in role, on death competency a Kruskal-Wallis test was run with years in role (1-5 years, 5-10 years, 10-20 years and over 20 years) as the independent variable and death competency as the dependent variable. The level 'under 1 year' for years in role was not included in this analysis as there were an insufficient number of participants in this group (n=9) to produce reliable results. This showed that there was no significant difference in death competency in relation to the number of years the person had worked in their role H(4) = 4.53, p = .339.

As qualitative analysis suggested a significant role of both challenge and controllability appraisals, the following two tests were run:

An independent samples t-test was conducted to determine whether there was a difference in SAM1 challenge scores between traditional (doctors and nurses) and non-traditional (EoL doulas) roles. Results indicated a significant difference between groups (t = -3.265, p < .001). The effect size was medium, with a Cohen's d of -0.62 (Cohen, 1988).

A Mann-Whitney U test was conducted to determine whether there was a difference in SAM1 controllable-by-self scores between traditional (doctors and nurses) and non-traditional (EoL doulas) roles. Results indicated a significant difference between groups, U = 2237.00, p = .036. The effect size, calculated as r = -0.17, indicated a small effect (Cohen, 1988).

#### 4.6.5 Exploring Possible Predictors of Death Competency

Finally, a correlational design was used to examine if death event appraisal of participants' first experience of a death, as measured by the Stress Appraisal Measure (SAM), which includes the subscales controllable-by-self, controllable-by-others, uncontrollable, challenge, threat, centrality, and overall stress, could predict death competency. Professional role (traditional vs non-traditional) was included as a moderator in the multiple regression to test the hypothesis that there would be a significant moderating effect of professional role on death competency. Correlations between the variables are shown in Table 12. Across all these variables, when focusing on correlation with death competency, we can see that the majority of correlations are very low – with correlations between death competency and SAM1

threat, SAM1 centrality, SAM1 uncontrollable-by-anyone, SAM1 controllable-byothers and SAM1 stress all close to 0. The two correlations of note are between death competency and SAM1 controllable-by-self, and death competency and SAM1 challenge. These correlations, whilst small, are significant at the p < 0.05 level and are denoted with an \*.

|                                      | Death<br>Compet<br>ency | Controll<br>able-by-<br>self | Threat | Centrali<br>ty | Uncontr<br>ollable-<br>by-<br>anyone | Controll<br>able-by-<br>others | Challen<br>ge | Stress |
|--------------------------------------|-------------------------|------------------------------|--------|----------------|--------------------------------------|--------------------------------|---------------|--------|
| Death<br>Compet<br>ency              | 1.000                   |                              |        |                |                                      |                                |               |        |
| Controll<br>able-by-<br>self         | 0.248*                  | 1.000                        |        |                |                                      |                                |               |        |
| Threat                               | -0.050                  | -0.462                       | 1.000  |                |                                      |                                |               |        |
| Centralit<br>y                       | -0.058                  | 0.000                        | 0.228  | 1.000          |                                      |                                |               |        |
| Uncontr<br>ollable-<br>by-<br>anyone | -0.080                  | -0.193                       | 0.525  | 0.032          | 1.000                                |                                |               |        |
| Controll<br>able-by-<br>others       | 0.084                   | 0.550                        | -0.401 | -0.027         | -0.363                               | 1.000                          |               |        |
| Challen<br>ge                        | 0.197*                  | 0.609                        | -0.162 | 0.294          | -0.268                               | 0.531                          | 1.000         |        |
| Stress                               | -0.060                  | -0.310                       | 0.739  | 0.544          | 0.428                                | -0.203                         | 0.090         | 1.000  |

 Table 12 Correlation Coefficients for Predictors (SAM1 Subscales) and Outcome Variable (Death Competency)

*Note*. This table shows correlations for SAM scores relating to appraisal of HCPs' first death event

Data were analysed using a Multiple Regression using the Enter Method. Durbin-Watson value was within the +-4 threshold. The regression equation was nonsignificant ( $R^2 = .121$ ,  $R^2Adj = -0.058$ ), indicating that the 7 subscales of death event appraisal were not significant predictors of death competency (F(14, 69) = 249.35, p = 0.789). Professional role (traditional vs non-traditional), as a moderator, did not significantly impact death competency.

Due to this non-significant finding a post hoc power analysis calculation with 7 predictor variables and 84 participants for a Multiple Regression with a medium effect size at a significance criterion of  $\alpha$  = .05 gives an observed power of 0.69. As this is below the recommended power of 0.8 (Coolican, 2018) it is acknowledged that the study had a smaller than ideal sample size resulting in the study being underpowered and therefore a higher chance of a type 2 error occurring.

The final section of this chapter will summarise the findings of this mixed methods study and discuss these in relation to the research questions and existing literature, present implications of these findings for practice, and outline strengths and limitations of the study.

## 4.7 Discussion

## 4.7.1 Findings Overview

This mixed methods survey reports findings from qualitative and quantitative data to understand how HCPs' individual appraisals of patient death events affect their death competency development, whether this differs by professional role, and what aspects of patient death event appraisal predict death competency development.

Findings from qualitative data suggest that HCPs' controllability and challenge appraisals are important aspects of patient death event appraisal for development of death competency, with quantitative findings also indicating a relationship between such appraisals and death competency. With regards to professional role, EoL doulas have significantly higher death competency than doctors and nurses and are more likely to appraise patient death events as a challenge, and as being an event that they could control. Additional findings from qualitative data were that early career patient death events cause intense emotional reactions in HCPs, and that the medicalisation of patients' deaths and attitude of death as failure can make these events more difficult for HCPs to cope with. Conversely, if patients actively collaborated with HCPs and those important to them to prepare for their death, this appeared to have a positive effect on how HCPs appraised and coped with their death.

Figure 8 presents a visual representation of how identified factors from qualitative and quantitative findings in this study may interact with one another to influence the development of death competency. The patient death event can lead to HCPs appraising the event in terms of the amount of control they had over the situation – judging the event to be controllable or uncontrollable, they may also appraise the event as a learning opportunity (challenge appraisal), they may also appraise the patient death as a 'good death', which is influenced by the patient's preparations prior to their death. Appraising the patient death as controllable, as a learning event, and as a good death all appear to be conducive with developing death competency. Appraisal of the event as uncontrollable appears to be unhelpful in terms of developing death competency, likely because this does not facilitate an increase in self-efficacy – a belief that the individual will be able to influence the outcome of a similar event in the future.

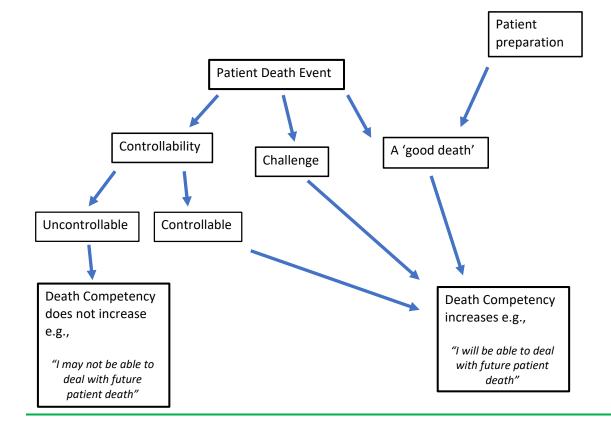


Figure 8 Interaction of Factors Involved in Death Competency Development

# 4.7.2 Discussion of Findings

Patient death events which appeared to be quite similar in terms of setting, nature of the death and support provided to the HCP could result in vastly different appraisals of the event. Based on the theory of appraisal, as described in the introduction to this chapter, this is expected as HCPs will have personal, subjective views of what happened during a patient death event based on their own evaluations and interpretations of what happened (Hwang, 2006).

Almost every participant could not only recall their first experience of being present at a human death event but could remember this in at least some detail. This supports previous research which has emphasised the importance and formative nature of these early career death events (Anderson et al., 2015; Bharmal et al., 2022; Schulz-Quach, 2018) and builds on these by providing detailed qualitative data regarding HCPs' recall and appraisal of details of these events, and novel information about how these events are formative (Hwang, 2006). The fact that for many participants their first experience of a death was the same event as their most memorable experience of patient death is consistent with existing literature. Previous research has found that a HCP's first experience of death and most memorable patient death are often one and the same event due to the newness of the experience causing strong emotional reactions; Rhodes-Kropf et al. (2005) reported that the "most memorable" patient death was also the first death experienced for at least 66% of participants in their study.

# Controllability

A central finding to the qualitative analysis, with mixed support from the quantitative analysis, is the role of controllability appraisals. Participants appraisal of a patient death as an event that was within their control appeared to foster more positive outcomes and increase the likelihood of the HCP feeling more competent in dealing with patient death. Findings from the controllability theme regarding HCPs shifting their focus from things they can't control to things they can, could have implications for training and debriefing. Facilitating this shift could be helpful for HCPs as it appears to positively influence their appraisal of and subsequent memory of the event. For example, it could be useful as part of the HCPs training to help them to

consider where their focus should be during a patient death event – ideally on the parts of the process that they can have a positive effect on - prior to being in this situation, and then again after the event to receive support to reflect on where their focus was directed and how this made them feel. It may be that the EoL doulas in this study were able to benefit from this focusing of attention more often than the HCPs in traditional roles, as a large part of EoL doula training is around identifying the parts of a death event which the doula can control and impact positively, for example advocating for the patient's wishes and preferences, making the environment comfortable and pleasant for the person and supporting those important to the person, whilst 'letting go' of the things they cannot control.

Another finding regarding controllability is that participant's view of whether the death event was controllable or not sometimes depended on availability of resources, such as pain medication, and of support from colleagues. There was also evidence that the actions of others could positively influence HCPs' view of the event as controllable as preparation on the part of patients for their own death, giving them control over decision making and allowing them to express their wishes, was helpful for HCPs' appraisal of the death event as a positive 'good death'. It is therefore important to consider the role of such external factors on individual appraisal and how patients are supported with such decision making as part of their care.

#### Death as Failure

Controllability was also relevant to other identified themes from qualitative data for example viewing the event as uncontrolled was associated with intense negative emotional reactions and viewing the death as a failure. Participants' narratives of deaths which they appraised as failures, presented in the 'death as failure' theme, were characterised by uncontrolled symptoms, medical emergencies, and a belief that they were personally unable to improve or influence the situation.

These descriptions in which participants described feeling more distressed because of what they perceived to be unnecessarily aggressive medical intervention is an interesting finding which adds a different perspective to existing research. Previous research has demonstrated that such medicalisation of the dying process and death can have negative impacts for patients such as continuation of futile treatment (Peters et al., 2013), however this study shows how this also has negative implications for the HCPs providing the care. Viewing these findings in the context of existing research suggests that medicalisation of death and dying and unnecessary life-prolonging medical intervention has a negative impact on all involved - patients, families, and HCPs. This negative appraisal by the HCP appeared to be linked to their personal beliefs and values regarding when life-sustaining treatment is appropriate, it may therefore be beneficial for HCPs to be supported to explore their views around this and to have the opportunity to discuss this in supervision and/or debriefing.

#### Challenge

Findings of this study also highlight how, despite negative experiences of patient death events, some participants were able to reframe these as positive learning experiences and opportunities for professional and personal growth – thereby demonstrating the significance of challenge appraisals on patient death events. Whether the HCP was able to reframe the event appeared to be influenced by their professional role, with EoL doulas being more likely to appraise their first experience of a death as a challenge. Those in traditional healthcare roles also described viewing patient death events as learning opportunities however they were more likely to focus on specific professional skills they had gained and could utilise in future similar situations, whereas EoL doulas tended to describe the patient death event as a profound, broader lesson in life and death, in one EoL doula's words, "the dying teach me how to die". It may be beneficial for doctors and nurses to be assisted to identify what they learned from the event and how this may lead to them providing better care to patients in the future. Such reframing may go some way to countering the potential negative effects of experiencing a difficult patient death such as the HCP being left with feelings of inadequacy and a loss of confidence. This also has implications for training of HCPs in traditional roles (doctors and nurses) in that there may be aspects of EoL doula training which could be incorporated into existing medical training in response to existing calls for additional support (Bowden et al., 2013; Centofanti et al., 2016; Charlton & Smith, 2000; Gibbins, McCoubrie & Forbes, 2011; Linane et al., 2019; Price & Schofield, 2015; Redman et al., 2017). This would serve to increase doctor and nurse's ability to appraise patient death events, even those which are difficult and traumatic, as opportunities for growth and learning. It

would be beneficial for future research to investigate what aspects of EoL doula training facilitate such appraisals.

#### **Emotional Intensity**

Far from being mundane 'everyday' events, this study provides further evidence that patient death events can be profoundly emotive, traumatic, and meaningful experiences for HCPs. The integrative nature of the theme of emotional intensity lends support to the important role of emotional intensity in existing areas of research both in death competency and event appraisal more broadly. The most intense emotional reactions described by participants appeared to be when the HCP perceived the patient to be suffering, which supports previous research (Jackson et al., 2005; Rhodes-Kropf et al., 2005) with the majority of emotions described by participants being negative. There was a noticeable difference between professional roles however, as EoL doulas were more likely to describe intense positive emotions in response to the patient death. This could be attributed to the fact that EoL doulas receive specific training in how to cope emotionally with the death of someone they are supporting and are encouraged to view death primarily as an opportunity for a meaningful ending to a life rather than an entirely negative occurrence. Again, it would be beneficial for further research to examine which parts of EoL doula training best prepare EoL doulas to deal with patient deaths and whether any of this training could be incorporated into training for medical students and student nurses before they encounter their first patient death event.

The qualitative data identified in the integrative theme 'emotional intensity' also highlighted how strong emotions including frustration, helplessness, and anger were associated with HCPs feeling that they had not been equipped with the skills required to cope with the patient death event and to provide high quality care to the patient. This has implications for staff training and support, suggesting that more training is needed to prepare HCPs prior to them experiencing their first patient death. Again this is consistent with existing research which has reported that HCPs themselves have called for additional training in this area due to them feeling ill-equipped (Bowden et al., 2013; Centofanti et al., 2016; Charlton & Smith, 2000; Gibbins, McCoubrie & Forbes, 2011; Linane et al., 2019; Price & Schofield, 2015; Redman et al., 2017).

# A 'Good Death'

The final identified theme, a 'good death', highlighted patient factors in HCPs appraisal of patient death events, specifically the benefits of preparation including advance planning, open conversations about death and dying between the patient and those close to them enabling care plans to be aligned with the patient's wishes and preferences. The benefits of advance planning are well documented in terms of benefits to patients themselves (Russell & Detering, 2017), but this study provides evidence of the potential benefits for HCPs when their patients actively prepare for their death. Whilst supporting and encouraging patients to prepare for the death is already an integral part of end of life care this finding suggests that the benefits of advance planning are even greater than has been reported to date, and that promoting patient preparation in hospital environments would have significant benefits for all involved – patients, families, and HCPs.

# 4.7.3 Strengths and Limitations

It is important to acknowledge limitations of this study to give context to findings and enable assessment of validity and credibility (loannidis, 2007). Firstly, the use of template analysis means that analysis can be influenced by researcher bias at various stages of analysis namely the selection of a priori themes, coding itself and interpretation (King, 2012) however existing research suggests that this risk can be mitigated using research reflexivity which is utilised heavily in this thesis with a dedicated reflexivity chapter (Chapter 5: Reflexivity). Secondly, the number of participants meant that quantitative analysis was underpowered meaning that there is a risk of a type II error (false-negative, resulting in a failure to reject a null hypothesis that is false). However, controllable-by-self and challenge appraisal variables were related to death competency, and these corresponded to the gualitative findings of this study demonstrating the strength of the mixed methods approach. With this in mind there is a clear rationale for revisiting a quantitative study in future to test this model specifically in relation to first death events. Such a study should also incorporate mood as a factor as the removal of this from the present study is a further limitation given that the qualitative findings demonstrated the role of emotion. Finally, the nature of an online survey and online participant recruitment may have meant that HCPs with higher death competency, who were therefore less

likely to avoid the subject of death and dying, may have been more likely to complete the survey meaning participants may not have been representative of doctors, nurses, and EoL doulas who would have reported lower levels of death competency. However, the fact that the Skew of death competency scores was within acceptable thresholds suggests that this was not an issue.

Despite these limitations, this study has several significant strengths. Firstly, the use of mixed methods to provide complementary data which fills existing gaps in the literature – namely knowledge regarding how HCPs appraise patient death events, what factors are important in the development of death competency in HCPs and how death competency differs between HCPs in traditional and non-traditional roles. Secondly, the use of mixed methods is a particularly 'good fit' for this topic, as it provides a means of moving between the exploration of individual factors, such as event appraisal, death competency and personal experiences of patient death, and the wider context of professional role - this is discussed in greater detail in Chapter 2: Methodology. Thirdly, the inclusion of both traditional and non-traditional HCP roles provides a previously unresearched insight into differences between these roles regarding patient death. This study also brings novelty to the field by providing new knowledge which enables us to understand how EoL doulas respond, appraise and cope with patient death and how this differs from traditional medical roles. Finally, this study provides an opportunity to consider how to use information and techniques from EoL doula training to educate and support HCPs in traditional medical roles.

# 4.8 Chapter Concluding Remarks

This chapter presented findings of a mixed methods study exploring how HCPs' individual appraisals of patient death events affect their death competency development and discusses implications of these findings. Throughout the process of this study, the researcher was herself practising as an EoL doula – one of the roles included in this study. The next chapter – Chapter 5: Reflexivity, will present an account of this 'insider and outsider' researcher practitioner position, which adds a further unique contribution within this PhD.

# **CHAPTER 5: REFLEXIVITY**

This chapter will present a reflexive account of my experience of being both a researcher studying EoL doulas and a practising EoL doula. It will explore the interaction between these two positions as 'insider' and 'outsider', how this position may influence my research and evidence how reflexivity has been used throughout this thesis to enhance the quality of this thesis as a whole. This chapter fulfils objective 5 of this PhD: To reflect on the process of conducting research into HCPs' development of death competency from the perspective of a trained end of life doula

# 5.1 Introduction

# 5.1.1 What is Reflexivity?

Reflexivity can be defined as "self-critical sympathetic introspection and selfconscious analytical scrutiny of the self as researcher", which recognises that research is a process, involving learning, influences from past experiences, reevaluation and the abandonment of previous ideas and aims for new ones (England, 1994, p.244). Reflexivity involves discussion and self-critique throughout a research project - as Davis (2020, p.12) put it, "reflexivity is not a destination, but a pursuit".

# 5.1.2 Why Engage in Reflexivity?

It is the researcher's responsibility to include and address the issue of reflexivity when doing qualitative research (Dodgson, 2019). Reflexivity is especially vital when conducting qualitative research, as researcher bias may affect the research process at any stage including the methods of data collection, how data is analysed and how findings are reported. By serving as a means to monitor the interplay between the involvement and detachment of the researcher, reflexivity can enhance the rigor and ethics of a study (Davis, 2020). It is not possible to completely prevent and control researcher effects, and reflexivity does not claim to do so, rather it is about identifying and revealing personal and relational subjectivity rather than preventing and controlling for effects on findings (Jootun, McGhee & Marland, 2009).

The qualitative methodology included in this PhD is enough to justify the need for a dedicated space for researcher reflexivity to be discussed, though the need is increased further by the fact that in the case of this PhD the researcher is both an

'outsider' researcher and 'insider' practising in the field. In other words, as Horsburgh, put it "the researcher is intimately involved in both the process and product of the research...it is necessary for the reader to evaluate the extent to which [the] author identifies and explicates their involvement and its potential or actual effect upon the findings" (Horsburgh, 2003, p. 309). Of course, it is not sufficient to simply include a chapter on reflexivity for a study to be deemed trustworthy and of high quality – reflexivity should be an active and ongoing process throughout the research (Johnson, Adkins & Chauvin, 2020), however this chapter aims to provide the information and insight the reader needs to complete their own evaluation of research quality.

From here on, in this chapter I will use the first person to facilitate self-reflection and enable me to share my own voice and perspectives in an authentic manner, as encouraged in previous research and reflexivity writings within the health and social care field (Davis, 2020; Patton, 2015; Peddle 2021). The content of this chapter follows recommendations by both Peddle (2021) on maintaining reflexivity in qualitative research and Davis (2020) on the presentation of reflexivity in the context of a PhD thesis.

# 5.2 Researcher Background

# 5.2.1 Wider Personal Influences

Before discussing my background specifically related to the topic of death competency, it is important to note several attitudes and beliefs I hold which may influence my research process.

The first of these is my feminist identity as a researcher. This brings with it assumptions and beliefs, such as a negative view of patriarchal systems which could be said to apply to traditional medical roles and healthcare systems. Researchers in feminist theory within Western medicine have identified how the biomedical model has its roots in patriarchal systems (Sharma, 2019), encouraging and prioritising approaches involving distance, objectification, certainty and rationality (Bleakley, 2013). This in turn creates barriers for more 'human-to-human' forms of healthcare delivery characterised by relationality, autonomy, appreciation before explanation (Bleakley, 2013; Shavisi, 2019) and a focus on learning with rather than learning

about the person (Kuper, 2007). I agree with these critiques and would align myself with the conclusions of these other feminist healthcare researchers in stating that I believe there is value in questioning the patriarchal values underpinning Western medical education. I can see how my support for 'non-traditional' roles such as that of EoL doulas serves this purpose by causing 'good trouble' (Malone & Yerger, 2020) to disrupt and challenge existing structures.

In terms of political views, I feel strongly that end of life care provision in the UK is underfunded, should be state funded, and that HCPs working in these settings should be better supported and paid. This was a contributing factor in my decision at the application stage of my PhD to focus on supporting HCPs to develop a positive trait (death competency) rather than reduce a negative (death anxiety) as I did not want the research and subsequent recommendations to be seen as blaming HCPs and wanted it to result in tangible recommendations for how we can provide better support.

Finally, my general worldview around the topic of death and dying is that death is simultaneously profound and 'every day', as Stephen Cave described it in one of the articles that began my interest in the topic, "both a tragedy and an insignificance" (Cave, 2014). I consider myself to be highly analytical and a 'deep thinker', and whilst this may in some ways lend itself to qualitative research, it also means that I tend to 'read into' others' stories and I may therefore have found more profound meaning in their words than they intended. Again, I took steps to mitigate these potential sources of bias through my research journaling, discussions with my supervisors and a constant effort to be aware of my own personal influence when conducting the analysis for this study.

#### 5.2.2 A Special Interest

In Robert Kastenbaum's The Psychology of Death, which has pride of place on my coffee table, he describes how as human beings we gradually learn when we are young that all living things will one day die: "Gradually, the child learns that some things do not return. "All gone" becomes one of the child's most popular expressions. In fact, the child may become a diligent researcher of the all-goneness phenomenon" (Kastenbaum, 2000, p.46). My family tells me that as a child 'gone' was one of my

first and favourite words and that I would repeat it whenever things passed by – cars, dogs, people, and remember carrying this interest with me through my childhood. I would watch wildlife in the garden, bring home dead birds and small mammals to study. The finite nature of all life on earth has fascinated me since I first learned about 'all-goneness', and indeed 30 years later here I am, sharing my journey to becoming a "diligent researcher of the all-goneness phenomenon".

My specific interest in the psychology of death and dying began during my first job after my undergraduate degree. I worked in the community in Leeds providing domiciliary care, often to people who had been discharged from hospital to die at home on 'fast track' programmes. Seeing the breakdowns in communication between the person who was dying, those close to them and their HCPs, and how this had negative consequences for all involved made me wonder 'how can we do this better?' When advocating for the person and those close to them, I saw how HCPs can often, with very good intentions, avoid giving the person and their family information, which only leads to more anxiety and distress. I found that people almost always had strong wishes and preferences around how they wanted their death to be - they knew where they wanted or did not want to die, for example. However, I also found that it was rare that the person had communicated these wishes and preferences to their loved ones and to the HCPs involved in their care the only people who could make those wishes a reality. This is supported by national statistics such as those from Marie Curie who report that 71% of people think that their wishes and preferences should take priority over those of their family or opinions of HCPs, yet only 14% had documented these (Marie Curie, 2021). I was surprised to find that even though everyone in the room knew the person was dying, it was rare that this was named, and HCPs often continued to talk in the language of 'cure', of preventing death and prolonging life, even when it was clear that the person did not want this and that they were accepting of the fact that they were dying.

A few years later I completed the foundation level of Living Well Dying Well's EoL doula training and began practising as an EoL doula in my community. Much of EoL doula training focuses on the idea of being 'your own first client' when it comes to helping someone confront their mortality – we must have confronted this ourselves first. It was clear, through the group feedback, that whilst doing this was difficult, it reduced death anxiety and meant that we were better placed to help others in turn with anything which involved conversations about death and dying, and with the dying process itself. I wondered whether HCPs have similar opportunities to develop such skills.

#### 5.3 Beyond the 'gap in the literature'

I found that the reality in the UK is that education for medical students around end of life care is limited and often inadequate (Walker at al., 2016) resulting in strong and repeated requests for additional training from junior doctors themselves (Bowden et al., 2013; Centofanti et al., 2016; Charlton & Smith, 2000; Gibbins, McCoubrie & Forbes, 2011; Linane et al., 2019; Price & Schofield, 2015; Redman et al., 2017). I became particularly interested in the question of how we can foster the development of 'human-to-human' ways of communicating between HCPs, patients, and their families, which seem to have been lost amongst the standardised 'communication skills' training formats. Historically many interventions which have aimed to teach HCPs end of life communication skills have been unsuccessful, demonstrating limited effects which were not maintained (Connors et al., 1995; Danis et al., 1991; Schniederman et al., 1992). More recent intervention studies have demonstrated that whilst communication training can increase HCPs' confidence in having end-of-life conversations, this does not appear to translate into increased frequency of conversations, or practical outcomes such as completion of advance decisions or palliative care referrals (Doorendos et al., 2016, Song et al., 2010).

Whilst studying health psychology, due to my interest in palliative care, I began reading further into this topic, and came across the literature on HCPs training and attitudes around 'death as failure'. This summed up what I had experienced working in previous roles and I become interested in how medical training sets HCPs up well for the medical aspects of their work which are essential for the majority of a patient's life where cure and treatment \*is\* the goal, but how this can be counter to the aims at the end of a person's life and how a curative focus and can become a barrier to good quality end of life care.

I started reading about death anxiety – my thinking being that if you 'dug down' beneath that professional role you would find just another human being who must deal with the fact that they too are mortal, whilst supporting others through dying and death. My health psychology Masters research, *How healthcare providers' own* 

death anxiety influences their communication with patients in end-of-life care: A thematic analysis explored this and found that HCPs' own death anxiety can act as a barrier to good-quality communication between them and the patient, and those important to the patient (Clare, 2020). Whilst I enjoyed researching this topic greatly, I was keen to focus on how we can support people to develop a positive trait rather than reduce a negative one, and therefore when it came to writing my PhD research proposal, I chose to focus on how we can help HCPs develop death competency, rather than how they can reduce their death anxiety.

By this time, I was not only working as an EoL doula myself but was also heavily involved in the development of a membership organisation for EoL doulas in the UK. I felt strongly that the doula roles core themes of flexibility and consistency, of being comfortable with the unknown, of making a conscious effort to stay in the space between, without concretising, enables a unique role with unique benefits, perfectly suited to filling gaps in existing support and working alongside traditional/mainstream health and social care services. I was therefore keen to include this relatively new and very under-researched role alongside 'traditional' HCP role in my research; both as a comparison but also to explore strengths and limitations of different roles when it comes to supporting a person through the dying process and at the point of death.

After reading research by Anderson, Kent & Owens (2015) and Kathryn Mannix's *With the End in Mind* (2018), who talk about the 'narratives' of a death event and how this can affect a person's anxiety around death and dying I became interested in how our experiences of death can influence our attitudes to death and dying. Mannix speaks about the importance of providing information and checking understanding with a person's loved ones when they are witnessing the dying process and how misunderstandings about physical changes and their own personal evaluations of these can affect how they go on to grieve and talk about the experience to others. I wondered whether this is also true of HCPs. For example, when they experience a patient death event, does the narrative they form around this affect how able they feel to deal with death and dying in the future? In psychological terms, this would be known as appraisal of the death event. My research question therefore began to take shape as 'does how HCP's appraisal of patient death events early in their career affect their subsequent death competency?' and 'what are the key factors in death competency development?'

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#### 5.4 Process

## 5.4.1 Reflexivity in Introduction

In the opening chapter of my thesis, Chapter 1: Introduction and Background, I include a reflexivity statement explaining my positioning as an 'insider' and 'outsider' researcher and my personal opinions regarding HCPs' roles and the current climate in which they are working.

"In addition to considering the wider context of the Covid-19 pandemic. another important positioning of this thesis related to the position of the researcher, who is both an 'insider' within the population being studied as a practising EoL doula, and an 'outsider' researcher studying this role. It is important to reflect on how this position may influence this thesis and studies contained within it from the outset, to minimise any potential negative researcher effects. In terms of personal stance, the researcher believes that the ethos and training underpinning the EoL doula role results in a valuable and complementary alternative to healthcare services based on the medical model. At the same time, as someone who has worked in NHS roles for much of my career to date and who believes strongly in the ethos of the NHS, this PhD is being undertaken with a personal goal of wanting to support NHS staff in dealing with patient deaths particularly in the current climate where due to the pandemic, along with over-stretched services and a lack of funding, healthcare professionals working in hospital settings are under immense pressure".

By stating this from the outset, it makes my reflexivity process visible and prompted me to consider this from the start of my research process and ensure this thread of active reflexive practice runs through this thesis from start to end.

#### 5.4.2 Reflexivity in Methodology

A key step in choosing research methodology is to explore, identify and accept one's own research philosophy Davis (2020). In the interests of being a reflexive and transparent researcher I report my worldview, assumptions, and position within the creation of new knowledge in my Methodology chapter. "..the researcher is taking a critical realism stance, believing that death events and the appraisal of these are influenced by structures, social phenomena including relationships and language and other event processes, and our study of such events is therefore fallible, yet still amenable to empirical study and that this is a valuable endeavour".

I also highlight in my Methodology chapter my awareness of how my chosen method of analysis could be influenced by myself:

"In relation to template analysis used in this study, a common example of bias is being emotionally swayed by reading a participant's story resulting in the researcher attributing a theme to the data that was not present (King, 2012). It is especially important to consider this possibility in the case of this study, which required the researcher to read detailed descriptions of death events which in many cases were highly emotive. The researcher took steps to mitigate this, both for quality of data analysis reasons and for self-care, by a) allowing time between readings to process the information and b) ensuring that coding was not done immediately after initial read-throughs when the information was most 'fresh' and emotive".

#### 5.4.3 Reflexivity in Literature Review & Meta Synthesis

The process of conducting my literature review and meta-analysis involved several decisions which I found challenging, and which required me to be aware of my own bias in terms of what I hoped the review would find. The first example of these was when deciding on the scope of my review. I had wanted to include EoL doulas in the review topics and search terms however a preliminary search identified that there were no existing articles relating to how EoL doulas cope with the death of a person they are supporting. I then decided to conduct a review of existing literature around death competency of HCPs however this resulted in finding only one study. Whilst these were important findings to discover, I felt concerned at this point that I did not have a review topic which was substantial enough to warrant a stand-alone PhD study and which would form a suitable foundation for my survey study. It was through using my research journal that I was able to see the issue which arose at this point –

I was making the decision based on the wrong focus, anticipating what I wanted to find in order to decide on my research question. When I noticed this I wrote in my journal:

..this makes me think that I have both jumped a step ahead and am also wrongly focusing on what I want the review to find rather than conducting the review to find out the true answer. I also feel I am too 'zoomed in' to think of my literature review research question and knowing what has worked in the past – stepping back, going for a walk, remembering what [supervisor] says that thinking is part of the work. Next step is to go back to the bigger picture – what do I need to know the answer to before doing my own study?.. [EC journal entry June 2020]

This felt like a turning point. Instead, I used my journal to ask myself 'what literature review research question do I need to know the answer to before undertaking my mixed methods study?' and 'what assumptions am I making when planning my mixed methods study?'. The answers were as follows:

...I realise that when thinking ahead to conducting my own study into death competency development I am making a number a significant assumption. I am assuming that healthcare professionals do not cope well with patient deaths, this feels likely due to a combination of the findings from my MSc research where participants told me that they struggled with these events, and largely due to my own bias that end of life doulas are better prepared to cope with such events. I therefore need to start by conducting my literature review to find out what is already known about how healthcare professionals cope with patient deaths, so that I am basing my study on evidence and not an assumption, and so that any recommendations I make can be informed by existing knowledge on the subject.. [EC journal entry July 2020]

Looking back at these entries, and knowing what I have done since, it seems almost too obvious to state these things, like there is no value in reporting this decision making process. However, I believe it is important to demonstrate how I identified and took steps to avoid my bias negatively impacting my research and to also serve as a reminder that it is sometimes hard to 'see' issues of bias when as a researcher you are immersed in the process and subject.

#### 5.4.4 Reflexivity in Mixed Methods Survey Study

At times during the process of conducting the survey study, I had to make a conscious effort to switch from thinking as a practitioner to a researcher, with a common example being that when reading responses from EoL doulas to a patient death and what they did in these situations, my immediate reaction was to think of how I would advise them to change this. In my work as an EoL doula I mentor doulas and provide CPD to help them improve their practice. Much of this involves reading written accounts of what doulas have done when supporting someone at the time of death, with my role being to provide feedback and constructive criticism where appropriate. In contract to this, when reading accounts of patient deaths from EoL doulas as a researcher undertaking this PhD, my role was to be non-judgemental and as neutral as possible when identifying themes in the qualitative data. This was a challenging shift to make, but one that I hope to have achieved as far as possible using my research diary and supervision. The following excerpt from my research journal demonstrates some of this process:

I felt somewhat torn today when reading through my data with a particular focus on the responses from EoL doulas. As a doula myself and a mentor for other doulas, I am finding it challenging reading descriptions of deaths where it sounds like the doula could have done more. And when I say done more I mean with a focus on the 'doing' and not just the 'being' – knowing when to switch between these two 'modes' is a key part of the doula role. Some accounts from doulas focus on the positives of being present at the death such as it feeling a privilege to witness and communicate a feeling of acceptance around the death being 'as it was', 'as it was going to be', almost a feeling of passiveness from the doula. I am finding reading some of these frustrating as I spend my own practise trying to 'myth bust' the idea that doulas are passive 'be-ers' rather than 'do-ers'. I am making an effort to be non-judgemental and remember I am a researcher in this context! [EC journal entry April 2022] A further challenge during the data analysis phase was the emotional reaction I experienced when reading through the data repeatedly to facilitate me gaining full familiarity with its content. Strong emotions came through almost all participant accounts, and it was impossible not to absorb these. Some participant accounts were harrowing and heart-breaking to read. Some were long and detailed, others so short that they were brutal and shocking to read. There were some descriptions that I did not want to read more than once. At the time, I reflected on how it may have been therapeutic for participants to have had the opportunity to share their story, and how I was in some ways pleased that I did not listen to these stories being told in real-time and in person.

At times I felt relieved that had to change methodology to a survey as hearing these stories in person would have been intense and difficult to not slip into being a practitioner rather than a researcher. There is of course no way of knowing how participants felt after taking part, but the fact that they chose to write in detail as part of an already lengthy questionnaire makes me think that there may have been some benefit to them in sharing their story. Or maybe I just want to think this! [EC journal entry March 2022]

Dealing with these emotional throughout data analysis required a keen sense of selfawareness to enable me to identify how I was feeling and whether this was due to things occurring in my own life or due to a response to reading and analysing the data. My research journal enabled me to work through these and identify what I needed, such as self-care, supervision and/or peer support.

#### 5.4.5 Reflexivity in Discussion

Finally in the discussion chapter of this thesis I acknowledge my own role as a researcher-practitioner as both a strength and a limitation.

A final strength and limitation of this thesis was the researcher's position as both the researcher and as a practising EoL doula. This experience benefitted this research as it provided an in-depth understanding of the EoL doula role and likely increased the number of EoL doula participants who were willing to take part in this research. It also allowed the inclusion of a novel reflexivity chapter exploring this unique positioning. However, this position was also a limitation as it had the potential to influence the analysis of qualitative data provided by EoL doulas and it was necessary for the researchers previous, personal understanding of how EoL doulas experience death events to be put to one side.

The 'putting to one side' of my own experience and beliefs regarding EoL doula practice was challenging, and it is not fully to completely disconnect from this human experience. Instead, the reflexivity and quality assessment methods used throughout this thesis mitigate the likelihood of my position influencing the results of this research; whilst the transparent reporting and reflection presented in this chapter allow the reader to draw their own conclusions as to the trustworthiness of the research contained within this thesis. To this end, the interplay between my role as researcher and practitioner will now be explored and presented.

#### 5.5 Research influencing practice; practice influencing research

Previous research has recommended that the 'insider' or 'outsider' status of the researcher is acknowledged (Collins, 1986). I was (and am) a practising EoL doula at the time this PhD was undertaken and hold a position of authority at the UK membership organisation for EoL doulas (EoLDUK). Therefore, when recruiting participants, I ensured that the request to participant did not come from myself in case EoL doulas felt pressure to participate due to my role. A further consideration arising from this was that by approaching this topic as a practising EoL doula, it could be said that I am likely to have a somewhat biased view of EoL doulas as representing a 'gold standard' in end of life care. However, much of my career to date has been within the NHS and I hope that by having 'one foot' in the more traditional medical cultural setting whilst also working in the EoL doula role, I see the value in both approaches and recognise how they complement each other, and how we need both to meet the increasing need for person-centred care at the end of life.

The first way that this PhD has influenced my practise is that is has made me more understanding when HCPs have difficulty communicating information about death and dying to people I am supporting as an EoL doula. As part of this role, I sometimes accompany a person to an appointment in which they are being given information about their diagnosis, prognosis, and treatment options. In the past, I felt very frustrated when the HCP having this conversation did not provide adequate information for the person to be able to make an informed decision, and especially if they seemed to be avoiding the topic. I felt strongly that this robs the person of the ability to decide what is best for them. I still believe this, however the process of conducting this researched has taught me that HCPs struggle to talk about death and dying just as much as anyone else, if not more sometimes due to the pressure on them to say the 'right' thing, and this has made me feel and react more compassionately towards them in these situations. In fact, I am now more likely to view the situation as one where I can support both the patient and the HCP to have this conversation.

Secondly, this research has made me critique the EoL doula training I received in terms of asking 'what is it about this training that fosters death competency development?' I have continued my EoL doula training whilst completing this PhD and the way that I viewed the process and content of this training at the beginning compared to now has changed. Previously, I had thought that it was the transfer of factual knowledge and skills, for example about symptoms of a human dying process, which were the key part of the training – the part which led to me and others reporting feeling much more competent in dealing with death and dying. However, as I have had to read and learn more about death competency development through this PhD, I have realised that in many ways it is the environment and individual 'self-work' that are key. The EoL doula training places you in a setting with others who are initially apprehensive about talking about death and dying and provides a safe and supportive space for you to gradually begin exploring your own mortality alongside others, to watch others doing the same which facilitates learning through modelling and to experience what is essentially graded exposure to thinking about death. The success of modelling and exposure in this setting is fitting with conclusions drawn by Robbins (1994) who referred to Bandura's theories of imitation and modelling leading to self-efficacy (Bandura, 1977) suggesting that a death competency intervention involving active participation was likely to have better outcomes.

Thirdly, this has in turn encouraged me to diversify my EoL doula practise from purely providing one-to-one support to people at the end of life, to also offering support to health and social care professionals to develop their death competency. Towards the end of this PhD, I piloted a workshop with health and social care professionals on 'death, dying and bereavement' with the aim of creating a space where attendees could explore and develop their death competency. I collected feedback as part of this and found that people reported, using items from the death competency scale as prompts for their own reflection, feeling more confident in coping with death and dying, more likely to start conversations with friends and family about death and dying and knowing what to do when somebody dies.

## 5.6 Examples of contribution to practice during this PhD

In this final section of this chapter, I present examples of by contribution to EoL doula practise during my PhD and align this with learning I gained from this research process to demonstrate the interplay between my research and practise and how each has benefitted from the other.

In September 2019 I was interviewed by a journalist from The Huffington Post for an article and video entitled 'I'm A 'Death Doula' – And It's Totally Changed the Way I See Life' which was published in November 2019 both online in written format and as a YouTube video (Moss & Johnston, 2019). This interview felt useful in terms of my professional development as it was the first time I had been asked to reflect, out loud, on the way that my EoL doula training and practice influenced my worldview – specifically how it encourages me to focus my time and energy on tasks that have meaning to me. I had started my PhD a few months earlier in June 2019 and this interview influenced my feelings about my research. The approach from a mainstream media outlet suggested to me that interest in the EoL doula role was growing and made me feel that the decision to include EoL doulas in my PhD was well timed.

In November 2021 I was interviewed for a piece in Artefact Magazine entitled Till Death Us Do Part along with four other EoL doulas (Loebig, 2022). To be featured alongside doulas such as Mary Clear, who epitomises the community, 'fellow citizen' nature of the role, talking frankly about transporting a body in the back of her car and 'try before you die' coffin sessions was a blunt reminder of what the EoL doula role means and can involve. At this stage of my PhD, I was beginning to analyse my data and had completed my literature review, and so was immersed in descriptions of medicalised deaths and the impact of ward culture. Contributing to this article allowed me to 'zoom out' to regain perspective on the many ways that death and dying can be approached and encouraged me to keep centring the uniqueness of the EoL doula role in my research.

In October 2022 I was interviewed for an independent documentary on Thanatophobia (death anxiety) (Hammett, 2022). This was filmed and directed by Simon Hammett who speaks openly about his own experience of death anxiety and who explained the debilitating nature of this to me prior to filming. This opportunity was the first time I had been invited specifically to talk publicly about death anxiety (as opposed to my EoL doula role), a concept closely related to death competency meaning this felt highly relevant to my PhD research.

In September 2022 I took part in the first International End of Life Doula Symposium, as a 'collaborator' with the role of shaping the event to ensure it was beneficial and relevant to an international audience. The event itself was held across three days and involved data collection from focus groups on the topics of 1) understanding individual practices and local priorities; 2) exploring overlap and differences in regional/national practices and concerns; and 3) mapping future interests across an international landscape. Findings, learning points and feedback from this event were collated into a report published by myself and colleagues (Krawczyk et al., 2022). At the time of this event, I had completed my literature review, data collection and analysis, and had started writing this thesis. The event made me reflect on how much the EoL doula role, 'movement' and awareness of the role had grown over the course of my PhD. Again, this gave me additional motivation as it was clear from the event and subsequent report that there is a need for research, such as this PhD, which explores EoL doula practice. It also highlighted how there exists a strong desire to conduct this amongst international academics - demonstrated by the fact that the first action point resulting from participant feedback was the need to form an international EoL doula research group.

# 5.7 Concluding Remarks

This chapter has presented and explored my position as a researcher-practitioner and demonstrated how reflexivity has been present throughout each stage of my PhD research process. It provides further and final necessary context ahead of the full discussion of PhD findings which follows in the next chapter.

# **CHAPTER 6: DISCUSSION**

This chapter summarises the findings of this thesis and discusses these in relation to existing literature and wider implications for practice. It begins by revisiting the research questions asked within this PhD, and the wider context in which this PhD took place. Key findings are then discussed in relation to existing research and potential applications, namely death competency and professional roles, death event appraisal, HCPs' training and wellbeing and implications for practice are outlined. Strengths and limitations of this thesis are then presented and finally recommendations for future research and the contribution of this PhD are summarised.

# 6.0 Review of Research Questions

This PhD investigated the role of patient death event appraisal in death competency development in HCPs. Data was collected via a systematic literature review and meta-synthesis, a mixed methods online survey enabling both quantitative and qualitative data on HCPs' individual experiences of patients' deaths and their appraisal of these, and a reflexive account of the researchers position as both a researcher and practitioner. The research questions for this PhD were "how do HCPs' individual appraisals of patient death events affect their death competency development and does this differ by professional role?" and "what aspects of patient death event appraisal predict death competency development?". These questions, along with the further aim of providing a reflexive account of the researcher's position as researcher and practitioner, resulted in the following objectives:

# Objectives

- To systematically review existing literature investigating psychological influences of HCPs' responses to patient death events, including their appraisal and coping strategies
- 2. To conduct a mixed methods exploration of HCPs' narratives of patient death events to investigate their appraisal of such events and their subsequent ability to develop death competency
- 3. To compare differences in patient death event appraisal according to professional training and identity focussing on traditional and non-

traditional healthcare roles specifically doctors, nurses, and end of life doulas

- 4. To identify potential predictors of death competency development following first experience of a patient death event
- 5. To reflect on the process of conducting research into HCPs' development of death competency from the perspective of a trained end of life doula

# 6.1 Summary of Findings

Analysis of both meta-synthesis and survey data was complementary, with qualitative data identifying the role of controllability and challenge appraisals and quantitative analysis finding that such appraisals were related to death competency. Death competency, controllable-by-self appraisals, and challenge appraisals were all found to differ between professional roles. In summary, this thesis tells us that two aspects of patient death event appraisal relating to HCPs' first experience of a death, namely controllability and challenge, may affect their death competency development and such appraisal differs depending on professional role.

# 6.2 Discussion of Findings

# 6.2.1 Death Competency and Patient Death Event Appraisal

The two central findings of this research are the role of controllability and challenge appraisal. Appraisal of participants' first experience of a death as controllable, and appraisal of the event as a challenge (an opportunity for learning or personal growth) were both key themes identified from qualitative data analysis, and quantitative data analysis found a positive relationship between these appraisal subscales and death competency, such that as controllable-by-self and challenge appraisals increased, so did the level of death competency. A significant difference in both types of appraisals was present depending on professional role, with EoL doulas reporting more challenge and controllable-by-self appraisals compared to traditional (medically trained) HCPs.

As quantitative analysis findings did not support a predictive role of controllability or challenge appraisals on death competency it is not possible from this research to know the nature of this relationship; it may be that appraisal of a patient death event as a challenge and/or an event within the person's control facilitated death competency development or, conversely, it may be that HCPs with higher death competency were more likely to appraise the death event as within their control or as a learning opportunity. The fact that this research focused on the person's *first* experience of a death, and it is unlikely that their death competency was high prior to them ever having experienced a death, suggests that the appraisal preceded death competency development. However, as the survey required appraisal of a past event this means that it is only possible to speculate on this relationship currently. It would be beneficial for future research to explore the direction of this relationship in further detail by considering how death competency may change and develop over time by using longitudinal data collection methods.

According to the transactional model of stress (Lazarus & Folkman, 1984), (see Chapter 1: Introduction and Background for a thorough overview of this model), challenge occurs as part of primary appraisal and controllability appraisals occur as part of secondary appraisal. Whilst it is accepted that this process is a complex and not always linear one, this suggests that in general, challenge appraisals may in turn influence controllability appraisals which in turn dictate levels of stress and subsequent coping strategies employed by the individual. As both challenge appraisal and controllable-by-self appraisal were found to be of particular importance in this current research, this suggests that the optimum condition for death competency development in terms of appraisal is for the HCP to appraise the patient death event as both a challenge *and* an event that is within their control. These findings are consistent with existing event appraisal research, for example challenge appraisals are known to reduce the likelihood that a person will view an event as a threat to their wellbeing, resulting in better event outcomes (Skinner and Brewer, 2002).

Effective coping is closely related to competence, as being able to successfully cope with a similar situation in the past means that the individual is more likely to perceive themselves as competent in dealing with this situation in the future (Liam, 2022). The findings of this PhD also relate to the coping aspect of the transactional model of stress by complementing existing research which has suggested that perceived sense of control is an important factor in coping, with a lack of perceived control

associated with disengagement coping strategies which can lead to more negative event outcomes (Carver and Connor-Smith, 2010).

In this PhD focusing on death competency, this means that HCPs who appraise a patient death event as controllable may be more likely to use engagement coping strategies which in turn may facilitate development of death competency. Alternatively, recognising that the transactional model of stress does not always function as a linear process and that coping in turn feeds back to inform individual appraisal (Goh, Sawang, & Oei, 2010; Lazarus & Folkman, 1984), it may be the case that HCPs appraised the patient death as controllable by themselves due to their use of engagement coping strategies, as previous research has found that such coping fosters an increased sense of controllability (Carver and Connor-Smith, 2010). There may also be an effect of challenge appraisals on the use of engagement coping as these are one of three aspects of resilience (Kobasa, 1979, 1982). This would be in line with previous research demonstrating that engagement coping facilitates the development of resilience following patient death events (Schulz-Quach, 2018).

#### 6.2.2 Death Competency and Professional Roles

EoL doulas and traditional medical HCPs have very different roles when present at a patient's death. The goal of doctors and nurses, dictated by the medical mandate, is primarily to prolong and sustain life (Peters et al., 2013; Meliones, 2000), whereas the goal of EoL doulas is to accept that the death is inevitable but to guide and be 'alongside' a person during the event (Elliott, 2011; Wolfelt, 1999). The finding that EoL doulas reported significantly higher levels of death competency than doctors and nurses in this study suggests that EoL doula training topics and methods may support the development of death competency. It is perhaps not surprising that EoL doulas scored higher on the Coping with Death Scale Short version as these subscales align with tasks that EoL doulas are trained to do as part of their role, specifically how to listen to those that are dying, how to help someone with their thoughts and feelings about death and dying and talking to friends or family members about their death. This contrasts with the fact that doctors and nurses receive little to no training related to aspects of death competency such as grief, dealing with one's own mortality and helping others explore their feelings about death, evidenced by existing research which has concluded that development of

training for doctors and nurses in death and dying is greatly needed (Bowden et al., 2013; Centofanti et al., 2016; Charlton & Smith, 2000; Gibbins, McCoubrie & Forbes, 2011; Linane et al., 2019; Price & Schofield, 2015; Redman et al., 2017). Whilst overall this finding may not be surprising, it is the first study to confirm that EoL doulas have higher death competency than HCPs in traditional medical roles and allows future research to build on this finding by exploring reasons for this and the nature of this relationship. Specifically, it would be useful for future research to explore whether EoL doula training leads to higher death competency, or whether individuals with higher death competency are more likely to undertake EoL doula training.

A second key finding related to professional role was from the qualitative data analysed from both the meta-synthesis and cross-sectional survey. This highlighted how viewing death as failure can be unhelpful for HCPs' development of death competency, and that this attitude was more salient in descriptions from traditional medical HCPs. As outlined in Chapter 1: Introduction and Background, there is an engrained attitude in hospital settings that patient death equals failure and that maintaining life should be HCPs' priority (Rhodes-Kropf et al., 2005). This thesis provides evidence that this attitude, driven by the underpinning 'medical mandate' of restoring patients to health (Meliones, 2000; Peters et al., 2013) can result in selfblame and guilt when HCPs are faced with patient death. Existing research has demonstrated the negative effects of such attitudes for patients such as futile treatment (Peters et al., 2013), however this PhD provides an alternative perspective which demonstrates how such attitudes can also have a detrimental effect on HCPs' wellbeing and development of death competency.

Death competency development is similar to, and in many ways synonymous with, personal growth. A growth mindset is therefore helpful for death competency development, and this is closely linked with challenge appraisal which involves viewing an event as an opportunity for personal growth (Peacock & Wong, 1990). EoL doula training may set individuals up for this form of death event appraisal by emphasising the role of the doula as one of 'being rather than doing', finding comfort in not having the answers, and focusing on curiosity and learning rather than providing expertise (Elliott, 2011; Wolfelt, 1999). In terms of experience measured by the number of years a person had worked in their role, no relationship was found between experience and level of death competency. This provides further evidence to highlight the contradictions already reported in existing literature regarding the relationship between experience in roles which have found no relationship Cheung et al. (2018), and that experience significantly predicted death competency (Chan et al, 2015; Ober, Granello & Wheaton, 2012).

# 6.3 Implications and Recommendations

# 6.3.1 For Patient Care

As this PhD focuses on factors which facilitate the development of death competency, and death competent HCPs are more likely to provide effective end of life care to patients (Robbins, 1992; Schmidt-RioValle et al., 2012), implications and recommendations discussed in this section have the potential to improve the care that patients receive by increasing HCPs' ability to support others with issues related to death and dying. Death competent HCPs are less likely to avoid conversations about death and dying (Braun, Gordon & Uziely, 2010; Ciakowska-Rysz & Dzieranowski 2013; Clare, Elander & Baraniak, 2020; Eggerman & Dustin, 1986), less likely to discuss advance planning and make timely referrals (Black, 2007; Reid et al., 2015) and better able to collaborate effectively with other HCPs when the patient is at the end of life (Black, 2007). This research therefore has the potential to influence improvements in patient and family satisfaction related to quality of end of life care.

# 6.3.2 For Practice

The main practical application of the importance of challenge appraisal in this PhD relates to debriefing practice. Whilst there is no single accepted definition of debriefing (Markulis & Strang, 2011), this typically involves a reflective discussion between teacher and student regarding their learning (Lederman, 1984).

The findings of this research suggest that debriefing may not have optimal benefit if it focuses purely on the factual nature of the event and HCP's practical learning, without allowing the HCP to discuss their personal interpretation (appraisal) of the

event, enabling this to be corrected or reassurance offered where needed, for example if the HCP appraised the death as a personal failure resulting in self-blame. This may be one reason why the structure and content of debriefing sessions have been judged to be inadequate by HCPs in previous studies (Tan, 2005). Debriefing without understanding individual HCPs' appraisal of a patient death and their role in this could increase the risk that they may find the debriefing session inconsistent with their views and therefore invalidating. For this reason, a recommendation for practice is that space to explore individual HCPs' appraisals following a patient death event should be provided at the start of a debriefing session so that the rest of the session can be tailored to the individual needs of HCPs following the event.

Debriefing sessions may also provide an opportunity to support HCPs to reframe patient death events, particularly in terms of enabling them to view the event as an opportunity for learning and personal growth (challenge appraisal) by exploring what they learned from the event and how they may use this to improve their practice in the future. This could potentially have multiple benefits for HCPs by a) increasing the learning potential of the patient death event thereby increasing death competency and b) countering the negative effects of a difficult patient death event.

Findings from this PhD also suggest that prebriefing, a technique which is already used to enhance learning and competency development in healthcare simulation training simulation (Page-Cutrara, 2014; Rudolph, Raemer & Simon, 2014), could be utilised to support HCPs to develop death competency. Prebriefing prior to a patient death event could enable HCPs to identify aspects of the patient death process which are within their control so that they can focus on these areas during the event, and key learning aims. By doing this prior to the patient death event the HCP may be more likely to appraise the event as within their control and as a learning opportunity – two aspects of appraisal which this PhD found are related to death competency development. This would require development of a tailored prebriefing intervention based on a standardised process of prebriefing, something which is yet to be established within the medical field (Dileone et al., 2020), and this is therefore an interesting focus for future research.

For these reasons, this research provides further weight to previously highlighted concerns that the importance of debriefing following a patient death is not

emphasised in medical students' training (Serwint, 2004; Shanafelt et al., 2012; Sharma, 2017).

# 6.3.3 For Healthcare Professionals' Training

The findings of this PhD have implications for the training of HCPs in traditional medical roles. Firstly, the results of this research demonstrate the need for prior training and a structured and supportive response following HCPs' first death event. If controllable-by-self and challenge appraisals are related to the development of death competency, fostering these during training may mean that HCPs in traditional medical roles are better prepared to deal with patient death. A means of doing this could be to support HCPs to identify key learning opportunities, and aspects of patient death events which are within their control and to prepare them to focus on these prior to them experiencing their first patient death.

Secondly, as this study found that EoL doulas have higher death competency and are more likely to appraise a patient death event as within their control and as a learning opportunity (challenge), it would be beneficial for the link between this and EoL doula training to be explored to identify what aspects of their training may facilitate this. A potential hypothesis for such future research could be that dedicating time to exploring one's own mortality and death anxiety in a supportive space and being comfortable with the unknown – both core parts of EoL doula training – promotes the development of death competency. Such aspects of EoL doula training could be adapted to support doctors and nurses to develop their death competency prior to experiencing their first patient death. This in turn could potentially have a protective effect on the evidenced negative impacts of an early career patient death, particularly in those cases where the HCP appraised the patient death as a failure, resulting in self-blame and guilt. This has implications for HCPs' wellbeing which will now be discussed.

# 6.3.4 For Healthcare Professionals' Wellbeing

This thesis provides further evidence that patient death events are highly emotive, meaningful and at times traumatic for HCPs, and that their early career experiences of such events can be particularly formative resulting in detailed memories and enduring emotions. The results of this research have the potential to inform interventions to promote development of death competency in HCPs, a trait which we know offers protection from compassion fatigue and burnout (Sanso et al., 2015).

Findings from the qualitative research elements of this PhD within both the metasynthesis and cross-sectional survey demonstrate how the attitude of 'death as failure' has negative effects on HCPs' wellbeing by a) increasing the likelihood of them experiencing self-blame as a reaction to the patient death and b) experiencing a negative emotional reaction due to witnessing patient suffering as a result of continuation of life sustaining treatment when the HCP viewed this as inappropriate. This highlights the importance of supporting HCPs to develop their ability to accept when a patient death is unpreventable and to turn their focus to preserving quality of life over quantity of life in these situations. This aligns with aspects of death competency, for example understanding the natural process of dying and knowing how to talk to patients about their wishes and preferences, thoughts, and feelings about death. Therefore, an implication of this finding is that by increasing death competency this may have a positive impact on HCPs' and patients' wellbeing by reducing self-blame and futile treatment.

Findings from the literature review and meta-synthesis (Chapter 2) suggest that pressure to remain 'professional' affects HCPs' initial reaction to patient deaths by dissuading them from expressing their emotions, resulting in 'emotional dissonance', which in turn is associated with burnout as it increases emotional exhaustion (Fiabane et al., 2019). This pressure appeared to inhibit HCPs' use of engagement coping strategies, which are known to be associated with lower stress levels in HCPs (Chao, 2011). An implication of these findings is that addressing the pressure to remain professional in hospital settings and actively encouraging the use of engagement coping strategies such as seeking social support from colleagues and utilising formal debriefing opportunities would likely have a positive effect on HCPs' wellbeing following a patient death event.

It was evident that there was a difference in such negative effects between traditional and non-traditional HCPs as EoL doulas were far more likely to describe their first experience of being present at a death as having a positive impact on their wellbeing and as an opportunity for growth (challenge appraisal) which was in turn supported by the quantitative data analysis. This suggests that there are aspects of EoL doula training and supervision which successfully prepare them for experiencing the death of a person they are supporting and protect the individual's wellbeing following this. It would therefore be beneficial for these aspects to be identified and adapted to provide support to HCPs in traditional medical roles, ideally before they experience their first patient death event to equip them with coping strategies required to minimise the negative impact on themselves.

As the findings of the systematic review and meta-synthesis study within this PhD identified, it is not possible to address aspects of patient death events which have a negative impact on HCPs' wellbeing without considering ward culture. The presence of ward culture which dissuades HCPs from seeking support and which perpetuates the attitude that emotional expression following a patient death is unprofessional and invalid, is likely to compound the negative effects of a patient death event. When considering ward culture in hospitals in the UK, it is important to recognise that this is likely to have changed due to the recent Covid-19 pandemic and this post-pandemic context will continue to influence culture within the NHS.

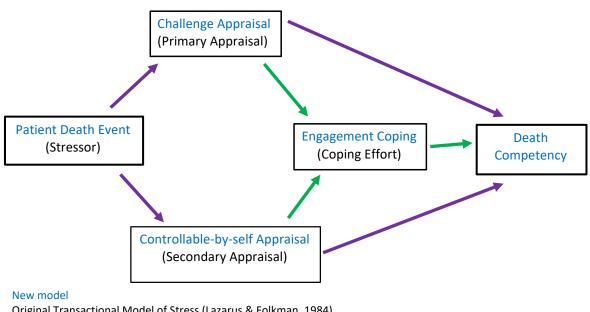
Indeed in relation to this wider context of this PhD, trainees are now going into a healthcare system post-Covid 19 pandemic, potentially with higher death anxiety and mortality salience (Cable & Gino, 2020; Hu, He, Zhou, 2020; Menzies & Menzies, 2020) and an increased risk of burnout post-pandemic (Selvaskandan et al., 2022; Sumner & Kinsella, 2021), making these implications of greater important and relevance compared to when this PhD began. Further exploration is therefore needed to explore these changes and to identify what implications this has for interventions which aim to promote death competency development in hospitals and improve staff wellbeing.

### 6.3.5 For Theory

The findings of this PhD also have implications for theory, specifically in relation to the transactional model of stress (Lazarus & Folkman, 1984). As outlined in Chapter 1 of this thesis, this model describes two key processes – cognitive appraisal of an event, split into primary and secondary appraisal, and subsequent coping. The key findings of this research focus on two types of appraisals contained within the transactional model of stress – challenge appraisal (primary appraisal) and

controllable-by-self appraisal (secondary appraisal), along with suggesting a possible mediating role of engagement coping. Figure 9 below provides a visual suggestion of how the findings of this PhD build on the transactional model of stress specifically in relation to patient death events, with development of death competency as the outcome. With the findings of this PhD paired with the transactional model of stress processes to demonstrate how death competency may develop in relation to appraisal of a patient death event, we can see that the patient death event (acting as the stressor) can lead to the HCP appraising this event as a learning opportunity (challenge appraisal) and as an event which is within their control, this in term may facilitate death competency development. This PhD also found a potential mediating role of engagement coping however this requires further research to explore the hypothesis that challenge and controllable-by-self appraisals increase the likelihood that the HCP will use engagement coping strategies which in turn promote death competency development.





Original Transactional Model of Stress (Lazarus & Folkman, 1984) Findings of this PhD Future research Further research is required to test and develop this model and to explore the potential mediating factor of engagement coping. This is one of several recommendations for future research which will now be discussed.

### 6.6 Recommendations for Future Research

This thesis provides a clear rationale for several areas of future research which will now be summarised. Firstly, it would be beneficial to clarify the nature of the relationship between controllable-by-self appraisal and challenge appraisal and death competency; specifically, to identify whether such appraisals promote death competency development, or whether individuals with higher death competency are more likely to appraise patient death events as controllable and as a learning opportunity. It would also be useful to explore whether this relationship constitutes a direct link or whether there is a mediating effect of engagement/disengagement coping. For example, it may be that by appraising the death event as controllable and/or as a learning opportunity the HCP feels more competent in dealing with patient death in the future – a direct link to death competency development. Alternatively, it may be that controllability appraisals increase the likelihood that the HCP will use engagement coping strategies and these in turn facilitate death competency development.

Further research should be conducted to determine which aspects of EoL doula training a) promote the development of death competency and b) increase the likelihood of controllable-by-self and challenge appraisals and explore how these training areas and techniques could be incorporated into existing traditional HCPs' training. It would also be important for future studies to clarify whether EoL doulas have higher death competency as a result of their training, or whether individuals with higher death competency are more likely to train as EoL doulas. A comparison of training for EoL doulas and medically trained HCPs could also identify topics and techniques used in EoL doula education particularly relevant to death competency development, and opportunities within medical training to incorporate these.

As emotion is a powerful shaper of memory and motivation to engage in or avoid highly emotional situations such as death events, this is an important focus for future studies. Such research should include an exploration of the role of emotion in patient death event appraisal and identification of any potential predictors of death competency, for example addressing the question of whether positive emotion following a patient death event is predictive of death competency or conversely whether negative emotional responses to patient death are indicative of a subsequent increase in death anxiety.

Finally, additional work is needed to build on this thesis to consider a theoretical model of how death competency develops, which could then be used to inform training and a debriefing intervention. Such research could also evaluate a prebriefing intervention, aimed at facilitating controllable-by-self and challenge appraisals following a patient death event and explore whether this increased the likelihood of such appraisals and any subsequent effect on death competency.

# 6.7 Strengths and Limitations

With regards to the strengths and limitations of this research, firstly, it was not possible to fully unpack the emotional component of patient death event appraisal within the quantitative data. As emotional states are closely linked with the transactional model of stress (Goh, Sawang, & Oei, 2010; Lazarus & Folkman, 1984) this is a key limitation. The inclusion of mood within the regression analysis could have demonstrated that mood state following appraisal of a patient death event is predictive of death competency. However, emotional expression and emotional intensity were central identified themes throughout the qualitative data collected and analysed in both the systematic literature review and meta-synthesis and survey study meaning this component and its potential effects are still accounted for and represented.

Secondly, the regression model used to explore possible predictors of death competency was non-significant, which may have been contributed to by a lack of power. However, two variables – challenge and controllable-by-self appraisals – were found to be positively related to death competency in line with qualitative data analysis findings. This highlights the strength of the mixed methods triangulation approach used in this thesis, which found that all findings point to the same factors – controllability and challenge appraisals, and role - as being important for death competency development.

The fact that data collection was limited to one time point – a change necessitated due to the Covid-19 pandemic, means that the potential to measure death competency development over time was lost. As highlighted in future recommendations for research, there remains a clear rationale for a study which measures death competency over time, again with a focus on early career experiences of patient death to potentially allow exploration of death competency before and after these events, particularly as this thesis provides further evidence of the formative nature of first death events.

A final strength and limitation of this thesis was the researcher's position as both the researcher and as a practising EoL doula. This experience benefitted this research as it brought an in-depth understanding of the EoL doula role and likely increased the number of EoL doula participants who were willing to take part in this research. It also allowed the inclusion of a novel reflexivity chapter exploring this unique positioning. However, this position was also a limitation as it had the potential to influence the analysis of qualitative data provided by EoL doulas and it was necessary for the researchers previous, personal understanding of how EoL doulas experience death events to be put to one side. Regular supervision exploring this positioning mitigated this limitation and the inclusion of Chapter 5: Reflexivity, where this issue is discussed in detail, ensures that any possible effects are openly discussed in a transparent and reflective manner.

# 6.8 Concluding Remarks and Summary of Original Contribution

This thesis informs us that the way in which HCPs appraise the patient death events they experience can influence their development of death competency. More specifically, the extent to which the HCP appraises the patient death event as being within their control, and as a learning opportunity, can influence the competence and confidence they develop. This thesis also suggests that EoL doulas appraise patient death events differently when compared to doctors and nurses and have higher death competency than HCPs in these traditional roles which has implications for practice, training, and staff wellbeing.

This thesis contributes new evidence regarding death competency, event appraisal and how HCPs cope with patient death. With no previous studies exploring factors which facilitate death competency development in HCPs, and the novel use of the SAM to apply to patient death events, this thesis makes an important contribution to death anxiety and death competency, and event appraisal fields. The inclusion of EoL doulas and exploration of how EoL doulas experience the deaths of those they support and how this compares to traditional healthcare roles makes this the first research of its kind.

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# **APPENDIX A – College Research Ethics Committee Approval**

Kedleston Road, Derby DE22 1GB, UK

T: +44 (0)1332 591060 E: researchoffice@derby.ac.uk Sponsor License No: QGN14R294

Dear Emma

ETH2021-3110

Thank you for submitting your application to the College of Health, Psychology and Social Care Research Ethics Committee, which has now been reviewed and considered.

The outcome of your application is:

Favourable opinion of amendments with conditions

Feedback on your application is available here.

If any changes to the study described in the application are necessary, you must notify the Committee and may be required to make a resubmission of the application.

On behalf of the Committee, we wish you the best of luck with your study.

# **APPENDIX B – Participant Information Sheet**

The development of death competency in healthcare professionals: The role of patient death event appraisal

#### **Information Sheet**

#### **Introduction**

Thank you for your interest in this study, which I (Emma Clare) am completing through the University of Derby in fulfilment of my Health Psychology PhD. This information sheet will explain the reasons for this research and what taking part in this study involves. After reading this information, please feel free to ask any questions you may have by using the contact details at the end of this document.

### Study Background

Death competency is defined as "a range of human skills and capabilities in dealing with death, as well as our beliefs and attitudes about these capabilities" (Robbins, 1994). Death competency is an important attribute for individuals who deal with death and dying as part of their professional role. Avoidance of conversations regarding death and dying by health workers in hospital settings has been identified as a significant barrier to provision of end-of-life care (Reid et al, 2013). Kessler, Heron & Dopson (2012) describe the lack of research into healthcare professionals' ways of dealing with death and dying as a "striking neglect". It has been theorised that avoidance and distancing from dying patients is a coping strategy for health workers' low levels of death competency, and that low death competency can lead to burnout, compassion fatigue and poor-quality patient-practitioner communication (Chi Ho Chan et al, 2015). It has therefore been argued that the development of death competency in healthcare professionals is an ethical issue.

#### What is the Purpose of this Research?

This study aims to explore how healthcare workers appraise patient death events and identify factors which facilitate the development of death competency. Identifying such factors could highlight areas where training and support are required, and where intervention would be most beneficial. This study aims to identify these key factors and use these to inform a model of death competency development. If we know what factors facilitate and promote the development of death competency, we can then provide more focused support to minimise the negative effects of death anxiety on healthcare professionals, such as burnout, and on patients' quality of care, in the form of avoidance of discussion regarding the patient's wishes and prognosis.

Who is Eligible to Participate?

Anyone working as a Doctor or Nurse in an NHS or private care hospital, or as an End of Life Doula in the UK who has experienced being present at a human death in a personal and/or professional situation.

# Do I have to take part?

No, it is entirely your decision whether you take part in this study or not. Your participation is voluntary and even if you decide to take part and complete the consent form, you can still choose to stop answering the questionnaire at any time. Questionnaires that are not completed and submitted will not be stored, so you can end your participation by closing your browser. If you have completed and submitted the questionnaire, you can withdraw your data from the study within 2 weeks of your participation by contacting the researcher and quoting your unique ID code generated at the start of the questionnaire.

# What will happen if I take part?

You will be asked to complete a series of short questionnaires, which will measure your death competency, death event appraisal and mood. You will also be asked to provide details of your experiences of being present at a death. Some of these questions will require you to tick a box to select an answer, and others will invite you to provide short written responses to describe situations you have been in and how you felt about these situations. Completing the questionnaire should take no more than 20 minutes. There are no right or wrong answers. Some questions will ask you to think about and describe your experience of being present at a death, if you feel distressed at any point please feel free to take a break from the questionnaire, you can come back to it later or end your participation at any time if you would like to.

You will also be asked to indicate whether you would be happy to be contacted to take part in two further follow up questionnaires, in 5- and 10-months' time. If you are happy to take part in these, you will be asked to provide a contact email address for us to send you the link to these questionnaires at later dates.

You will also be asked to indicate your interest in taking part in a follow up interview, which will focus on your experience of being present at a death. Should you indicate that you would be happy to take part in an interview, you will be asked to provide a contact email address. Not all participants who express interest in taking part in a follow-up interview will be contacted, however if you are selected to take part in an interview, we will send you further information about this study at a later date and invite you to participate. Even if you indicate that you would be happy to take part, you can still change your mind at any time.

## What will happen if I want to stop taking part?

You may withdraw from the study at any point up until two weeks after your participation without providing a reason and without any negative consequences. Should you wish to

withdraw whilst taking part, please close your browser and data will not be recorded. If you wish to withdraw after completing the survey, please contact the researcher at **<u>e.clare1@unimail.derby.ac.uk</u>** quoting your unique ID code which you will generate at the beginning of the online survey.

## Will taking part benefit me?

You will not receive any expenses or payments for participation in this research. The information you provide may help us to understand the support needs of healthcare professionals when they have been present at a death, and to recommend ways in which this experience could be improved for healthcare professionals, patients and families.

## What are the potential disadvantages/risks involved with taking part?

We do not think that there are any major risks to you taking part in this study. Due to the sensitive nature of the topic, it is possible that some questions may cause distress, if this happens please feel free to take a break from the questionnaire, skip this question or withdraw from the study. In the unlikely event that you require further support following taking part in this study, please find details of support services included both at the end of this document and in the debrief at the end of the study.

# What if I am unhappy or there is a problem?

Please feel free to let us know by contacting the researcher using the contact details at the end of this document and we will try our best to help. If you remain unhappy or wish to make a complaint following this, then you can contact the researchers' supervisor using the contact details at the end of this document, or Professor Claire Brindley via email c.brindley@derby.ac.uk or telephone 01332 592632.

## How will my data be used?

This study is being conducted in fulfilment of my Health Psychology PhD research. The data will be used to inform a thesis that will be submitted to the University of Derby. Your responses to the online survey questions will be analysed and shared in publications, reports, online, in conference presentations and other research outputs. Individual data will not be analysed. Direct quotes from your open-ended answers may be used for illustrative purposes within reports, but any quotes will be anonymised, and you will not be identifiable. Anonymised data may be submitted to academic journals as part of the publication process.

## Will my data be stored securely?

Your data will be stored anonymously on the University of Derby's secure server. Any personal contact details provided (in the form of email addresses) will be stored in password protected documents and separate to survey data. Only members of the research team will have access to your data. Your data will not be used in future research projects without your permission. Your data will be stored for 7 years and will be securely destroyed after this time in line with University of Derby data management policy. Personal data (email addresses) will be stored until you have completed the study, or if you withdraw from the study.

## **GDPR Statement**

Researchers will be collecting data from your participation in this project. We need these data to understand how we might best support healthcare professionals to develop their competence in dealing with death and dying, and in the public interest of enhancing academic

research. This is the legal basis on which we are collecting your data and while this allows us to use your data, it also means we have obligations towards you to:

- not seek more information from you than what is essential and necessary for the study
- make sure that you are not identified by the data by anonymising it using ID codes and pseudonyms
- use your anonymised data only for the purposes of this study and for any relevant publications that arise from it
- store data safely in password-protected databases to which only the named researchers have access
- not keep your information for longer than is necessary (usually for seven years)
- · safely destroy your data by shredding or permanently deleting them

The University of Derby will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. The researcher and supervisory team with access to the data are highly qualified and experienced and have been very careful to ensure the security of your data. The study was approved for its ethical standards by The University of Derby Human Sciences Research Ethics Committee. However, in the unlikely event that you feel you need to make a complaint regarding the use of your information, you can contact the Data Protection Officer at the University of Derby: James Eaglesfield (01332) 591762 or the Information Commissioners Office 0303 123 1113. Further information about the project can be obtained from the researchers, whose contact details are outlined at the end of this information sheet.

## **Contact Details**

If you would like to contact the researcher, you can do so by emailing Emma Clare at <u>e.clare1@unimail.derby.ac.uk</u>. If you would like to contact the researcher's supervisor you can do so by emailing Dr Amy Baraniak at <u>a.baraniak@derby.ac.uk</u> or calling 01332 59**3047**.

# **APPENDIX C – Informed Consent Form**

# The development of death competency in healthcare professionals: The role of patient death event appraisal

Thank you for agreeing to participate in this study.

Please use the link above to view the Participant Information Sheet. Please read this fully before deciding whether to participate in this study. After reading this, please read the following statements and use the tick boxes to indicate your response:

- I confirm that I have read and understood the Participant Information Sheet dated 24.08.20 and have fully understood the information provided.

- I have had the opportunity to ask questions and, if I have asked questions, I am satisfied with the answers I have received.

- I understand that my participation is entirely voluntary and that I may withdraw from the study at any time up until two weeks following participation without providing explanation and without any negative consequences.

- I understand that the data I provide will be kept confidential and stored securely and that only anonymised data will be shared publicly.

- I understand that anonymised quotes from my responses may be shared in publications, reports, online, in conference presentations and other research outputs.

- I understand that anonymous data from this study may be submitted as part of the academic publishing process.

- I agree to take part in this study

Please indicate whether you would like to take part in this study:

Yes, I provide my consent and would like to take part

No, I have decided not to take part

Thank you for your time. If you would like to contact the researcher, you can do so by emailing Emma Clare at e.clare1@unimail.derby.ac.uk .If you would like to contact the researcher's supervisor you can do so by emailing Dr Amy Baraniak at a.baraniak@derby.ac.uk or calling 01332 593047.

# **APPENDIX D - Online Survey**

# The development of death competency in healthcare professionals: The role of patient death event appraisal

# Participant Biographies

Age: Gender: Ethnicity:

Length of time in current role:

Please outline your current role and the setting you usually work in:

Has your role and/or setting changed during the COVID-19 pandemic? Please give details of any changes:

Please summarise any basic and additional training you have received in dealing with death and dying (open text):

# Experience including pre and during pandemic

Prior to the Covid-19 pandemic, I had been present at a patient's death:

- Never
- Rarely
- Occasionally
- Often
- Very often

During/since the start of the Covid-19 pandemic, I have been present at a patient's death:

- Never
- Rarely
- Occasionally
- Often
- Very often

Has how <u>you</u> deal with patient deaths changed as a result of the Covid-19 pandemic? If yes, please tell us how:

Prior to the Covid-19 pandemic I engaged in advance planning (DNACPR, Advance Decisions to Refuse Treatment, Lasting Power of Attorneys for Health and Welfare) conversations with patients:

- Never
- Rarely
- Occasionally
- Often
- Very often

During/since the start of the Covid-19 pandemic, I have engaged in advance planning (DNACPR, Advance Decisions to Refuse Treatment, Lasting Power of Attorneys for Health and Welfare) conversations with patients:

- Never
- Rarely
- Occasionally
- Often
- Very often

Please list or describe key features of a typical human dying process:

I feel that I have a good understanding of what a typical human dying process looks like

Strongly Disagree Disagree Neutral Agree Strongly Agree

## **Death Event Appraisal**

How would you describe your first experience of being present at a human death? You might consider the extent to which you feel the death was peaceful, preventable, traumatic, well-managed, gentle etc, but please go beyond these suggestions (open text):

Holding your first experience of being present at a human death in mind, please now complete the following questionnaire for this event:

\*Stress Appraisal Measure (SAM) Peacock, E. J., & Wong, P. T. P. (1990). The Stress Appraisal Measure (SAM): A multidimensional approach to cognitive appraisal. *Stress Medicine*, *6*, 227-236.

How would you describe your most memorable patient death? You might consider the extent to which you feel the death was peaceful, preventable, traumatic, well-managed, gentle etc, but please go beyond these suggestions (open text):

Holding your most memorable patient death event in mind, please now complete the questionnaire for this event:

\*Stress Appraisal Measure (SAM)

We would now like you to imagine the next time that you expect to death with a patient death, for example at some point within the next 3 months. Please complete the questionnaire a final time for this imagined future death event:

\*Stress Appraisal Measure (SAM)

### <u>Mood</u>

Existing measure - Abbreviated Profile of Mood States

Test Bank Code: U419

Grove, J. R., & Prapavessis, H. (1992). Preliminary evidence for the reliability and validity of an abbreviated Profile of Mood States. *International Journal of Sport Psychology*.

### **Motivational Congruence**

How we perceive an event depends on whether we feel the situation is consistent, or inconsistent, with our personal goals. Therefore, our experience of a death event depends on what our personal goals were during the event.

How would you describe your ultimate goal (for yourself, for the person dying, for others) during your first experience of being present at a human death?

Do you feel that you achieved this goal? If yes, what factors do you feel enabled you to achieve this? If no, what factors do you feel prevented you from achieving this?

If you were to be in this situation again in the future, do you think that your goal would be different?

If you were to be in this situation again in the future, how confident are you that the outcome of the situation would match your goal?

| Very Confident | Confident | Neutral | Unconfident | Very unconfident |
|----------------|-----------|---------|-------------|------------------|
|----------------|-----------|---------|-------------|------------------|

How would you describe your ultimate goal (for yourself, for the person dying, for others) during your most memorable patient death?

Do you feel that you achieved this goal? If yes, what factors do you feel enabled you to achieve this? If no, what factors do you feel prevented you from achieving this?

If you were to be in this situation again in the future, do you think that your goal would be different?

If you were to be in this situation again in the future, how confident are you that the outcome of the situation would match your goal?

Very Confident Confident Neutral Unconfident Very unconfident

### Death Competency

Existing measure – Coping with Death Scale Short Version

Test Bank Code: U1103

### Thank you and Follow-Up

Thank you for taking part in this study, your time is much appreciated. As part of this study, we are hoping to collect follow-up data in Spring/Summer 2021. Please use the following tick boxes to indicate whether you would be happy to take part in the future.

Would you be happy to take part in a follow-up online survey? Yes \_ No \_

Would you be happy to take part in a follow-up interview? Yes \_ No \_

If you have answered Yes to either/both questions, <u>please click here</u> to register your interest (this ensures that your contact information is not linked to your responses in this survey)

# **APPENDIX E – Interim Debrief**

The development of death competency in healthcare professionals: The role of patient death event appraisal

# Interim Debrief

Many thanks for taking part in this study – your time is much appreciated.

### What Happens Now?

As part of this study, we are hoping to collect follow-up data in Spring/Summer 2021. At the end of the survey questions you will have been asked whether you would be happy to be contacted to take part in follow-up online surveys and/or an interview and if so, will have been invited to <u>click on this link</u> to register your interest.

### **Background Information**

This study is investigating the development of death competency in healthcare professionals, a term which refers to our skills, capabilities, beliefs and attitudes in dealing with death (Robins, 1994). It has been recognised in recent decades that the first experience of a patient's death can have a significant impact on future practice by leading to feelings of helplessness, defensiveness and distress, resulting in coping strategies such as distancing, emotional suppression and avoidance (Anderson, Kent & Owens, 2015). Avoidance of conversations regarding death and dying by health workers in hospital settings has been identified as a significant barrier to provision of end-of-life care (Reid et al, 2013). This avoidance and distancing from dying patients has been theorised to be a coping strategy for health workers' low level of death competency.

## Why is this Important?

Identifying predictors of death competency could highlight areas where training and support are required, and where intervention would be most beneficial. If we know what factors facilitate and promote the development of death competency, we can then provide more focused support to minimise the negative effects of death anxiety on the healthcare professional, such as burnout, and on patients' quality of care. This study aims to identify these key factors and use these to inform a model of death competency development.

### **Further Information**

If you would like to receive a summary of the key research findings from this study once the study and research report has been completed, please email the researcher at the email address below.

## What if I want to withdraw from the study?

Should you wish to withdraw from this study you may do so within two weeks of your participation, without providing an explanation and without any negative consequences for yourself. If you wish to withdraw please email the researcher at the email address below, quoting your unique ID code which you will have generated at the start of the online survey. This ID code will be in the format first two letters of your postcode, last two digits of your telephone number, your year of birth (e.g. YO821990), we encourage you to make a note of this code and keep it in a safe place should you need it following your participation in this study.

## How will my data be used?

This study is being conducted in fulfilment of my Health Psychology PhD research. The data will be used to inform a thesis that will be submitted to the University of Derby. Your responses to the online survey questions will be analysed and shared in publications, reports, online, in conference presentations and other research outputs. Individual data will not be analysed. Direct quotes from your open-ended answers may be used for illustrative purposes within reports, but any quotes will be anonymised and you will not be identifiable. Anonymised data may be submitted to academic journals as part of the publication process.

# Will my data be stored securely?

Your data will be stored anonymously on the University of Derby's secure server. Any personal contact details provided (in the form of email addresses) will be stored in password protected documents and separate to survey data. Only members of the research team will have access to your data. Your data will not be used in future research projects without your permission. Your data will be stored for 7 years and will be securely destroyed after this time in line with University of Derby data management policy. Personal data (email addresses) will be stored until you have completed the study, or if you withdraw from the study.

## **GDPR Statement**

Researchers will be collecting data from your participation in this project. We need these data to understand how we might best support healthcare professionals to develop their competence in dealing with death and dying, and in the public interest of enhancing academic research. This is the legal basis on which we are collecting your data and while this allows us to use your data, it also means we have obligations towards you to:

- not seek more information from you than what is essential and necessary for the study
- make sure that you are not identified by the data by anonymising it using ID codes and pseudonyms
- use your anonymised data only for the purposes of this study and for any relevant publications that arise from it
- store data safely in password-protected databases to which only the named researchers have access
- not keep your information for longer than is necessary (usually for seven years)
- safely destroy your data by shredding or permanently deleting them

The University of Derby will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. The researcher and supervisory team with access to the data are highly qualified and experienced and have been very careful to ensure the security of your data. The study was approved for its ethical standards by The University of Derby Human Sciences Research Ethics Committee. However, in the unlikely event that you feel you need to make a complaint regarding the use of your information, you can contact the Data Protection Officer at the University of Derby: James Eaglesfield (01332) 591762 or the Information Commissioners Office 0303 123 1113. Further information about the project can be obtained from the researchers, whose contact details are outlined at the end of this information sheet.

## Support Services

Due to the sensitive nature of the topics discussed during this interview, it is entirely natural and understandable for you to experience emotional reactions following your participation in this study. Should you wish to seek support, please find signposting information below:

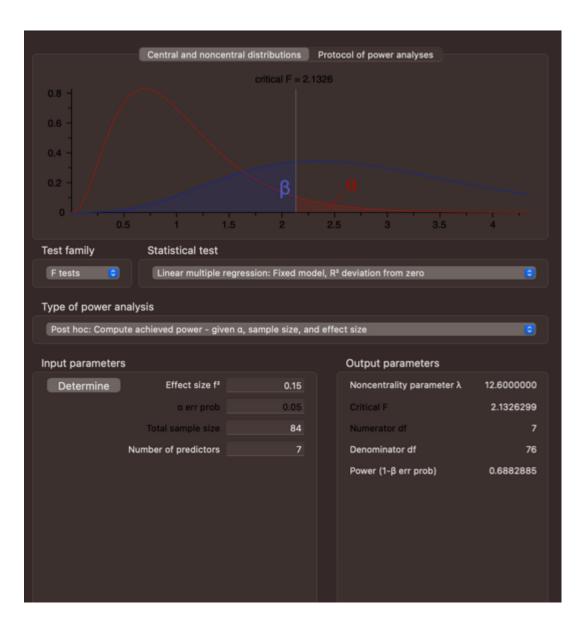
For North East NHS Trusts: Alliance Workplace Counselling (Free for NHS staff): Freephone 0800 107 5880

Cruse Bereavement Care freephone national helpline: 0808 808 1677

You can also refer to your weekly NHS trust emails for details of your internal employee support services.

<u>Any Questions</u> If you have any questions, please feel free to email the researcher at the email address below.

Thank you again for your time. If you would like to contact the researcher you can do so by emailing Emma Clare at e.clare1@unimail.derby.ac.uk .lf you would like to contact the researchers supervisor you can do so by emailing Dr Amy Baraniak at a.baraniak@derby.ac.uk or calling 01332 593047.



# **APPENDIX F – G-Power Analysis**

# **APPENDIX G – Data extraction sheet**

# DATA EXTRACTION SHEET

# What are the psychological influences on healthcare professionals' coping responses to early career patient death events?

Reviewer Initials:

# **Identifying Information**

| Reference     | Title:             |                    | Authors: |
|---------------|--------------------|--------------------|----------|
| No:           |                    |                    |          |
|               |                    |                    |          |
| 6             |                    |                    |          |
| Source:       |                    | Research Question: |          |
|               |                    |                    |          |
|               |                    |                    |          |
|               |                    |                    |          |
| Type of study | : Review / Primary |                    |          |
| data / Other  | (specify)          |                    |          |
|               |                    |                    |          |
|               |                    |                    |          |
|               |                    |                    |          |

### Study Details:

| Study design (must be qual):   | Recruitment Method: | Country: |
|--|---------------------|----------|
| How long after patient death was data collected<br>(must be investigating reaction to patient death<br>rather than grief at a later time)? |                     |          |

| Method (interview/diary/focus group etc),<br>including how response to patient death explored<br>(e.g. What questions asked): |  |  |  |  |  |  |  |  |
|---|--|--|--|--|--|--|--|--|
|   |  |  |  |  |  |  |  |  |
| No. of participants:  | Sample inclusion criteria:   |  |  |  |  |  |  |  |
| Refusal rate:   | Sample exclusion criteria:   |  |  |  |  |  |  |  |
| Participant details (e.g. rol<br>training, age, ethnicity, ger  | e, setting (must be hospital setting), time in role, experience,<br>nder): |  |  |  |  |  |  |  |
| Analytic strategy: (IPA/thematic/discourse analysis, etc.)  |  |  |  |  |  |  |  |  |

# **APPENDIX H – SPSS Output**

### **Descriptive Statistics**

|                           | N         | Range     | Minimum   | Maximum   | Mean      | Std.<br>Deviation | Skev      | vness      | Kur       | tosis      |
|---------------------------|-----------|-----------|-----------|-----------|-----------|-------------------|-----------|------------|-----------|------------|
|                           | Statistic | Statistic | Statistic | Statistic | Statistic | Statistic         | Statistic | Std. Error | Statistic | Std. Error |
| Death Competency<br>Total | 94        | 59.00     | 4.00      | 63.00     | 29.5213   | 18.81245          | .366      | .249       | -1.209    | .493       |
| Valid N (listwise)        | 94        |           |           |           |           |                   |           |            |           |            |

|                   | Descriptive                         | s           |                    |            |
|-------------------|-------------------------------------|-------------|--------------------|------------|
|                   |                                     |             | Statistic          | Std. Error |
| SAM1_CONTROL_SELF | Mean<br>95% Confidence Interval     | Lower Bound | 14.4493<br>13.8221 | .31719     |
|                   | for Mean                            | Upper Bound | 15.0765            |            |
|                   | 5% Trimmed Mean                     |             | 14.5797            |            |
|                   | Median                              |             | 15.0000            |            |
|                   | Variance                            |             | 13.884             |            |
|                   | Std. Deviation                      |             | 3.72616            |            |
|                   | Minimum                             |             | 4.00               |            |
|                   | Maximum                             |             | 20.00              |            |
|                   | Range<br>Interquartile Range        |             | 16.00<br>5.00      |            |
|                   | Skewness                            |             | 442                | .206       |
|                   | Kurtosis                            |             | 327                | .410       |
| SAM1_THREAT       | Mean                                |             | 7.2681             | .27223     |
|                   | 95% Confidence Interval<br>for Mean | Lower Bound | 6.7298             |            |
|                   |                                     | Upper Bound | 7.8064             |            |
|                   | 5% Trimmed Mean                     |             | 6.9871             |            |
|                   | Median                              |             | 7.0000             |            |
|                   | Variance<br>Std. Deviation          |             | 10.227<br>3.19795  |            |
|                   | Minimum                             |             | 4.00               |            |
|                   | Maximum                             |             | 19.00              |            |
|                   | Range                               |             | 15.00              |            |
|                   | Interquartile Range                 |             | 4.25               |            |
|                   | Skewness                            |             | 1.083              | .206       |
|                   | Kurtosis                            |             | .908               | .410       |
| SAM1_CENTRAL      | Mean                                |             | 11.8116            | .38874     |
|                   | 95% Confidence Interval<br>for Mean | Lower Bound | 11.0429            |            |
|                   |                                     | Upper Bound | 12.5803            |            |
|                   | 5% Trimmed Mean                     |             | 11.7907            |            |
|                   | Median<br>Variance                  |             | 12.0000<br>20.855  |            |
|                   | Std. Deviation                      |             | 4.56670            |            |
|                   | Minimum                             |             | 4.00               |            |
|                   | Maximum                             |             | 20.00              |            |
|                   | Range                               |             | 16.00              |            |
|                   | Interquartile Range                 |             | 7.00               |            |
|                   | Skewness                            |             | .114               | .206       |
|                   | Kurtosis                            |             | 879                | .410       |
| SAM1_UNCONTROL    | Mean                                |             | 9.4565             | .32576     |
|                   | 95% Confidence Interval<br>for Mean | Lower Bound | 8.8124             |            |
|                   | 5% Trimmed Mean                     | Upper Bound | 10.1007<br>9.3478  |            |
|                   | Median                              |             | 9.0000             |            |
|                   | Variance                            |             | 14.644             |            |
|                   | Std. Deviation                      |             | 3.82676            |            |
|                   | Minimum                             |             | 4.00               |            |
|                   | Maximum                             |             | 18.00              |            |
|                   | Range                               |             | 14.00              |            |
|                   | Interquartile Range                 |             | 6.00               |            |
|                   | Skewness                            |             | .317               | .206       |
| SAM1_CONTROL_OTHE | Kurtosis                            |             | 860                | .410       |
| RS                | Mean<br>95% Confidence Interval     | Lower Bound | 12.6159<br>11.9093 | .35738     |
|                   | for Mean                            | Upper Bound | 13.3226            |            |
|                   | 5% Trimmed Mean                     |             | 12.6618            |            |
|                   | Median                              |             | 12.0000            |            |
|                   | Variance                            |             | 17.625             |            |
|                   | Std. Deviation                      |             | 4.19823            |            |
|                   | Minimum                             |             | 4.00               |            |
|                   | Maximum                             |             | 20.00              |            |
|                   | Range                               |             | 16.00              |            |
|                   | Interquartile Range<br>Skewness     |             | 6.00               | .206       |
|                   | Kurtosis                            |             | 662                | .200       |
| SAM1_CHALLENGE    | Mean                                |             | 12.3986            | .30207     |
|                   | 95% Confidence Interval             | Lower Bound | 11.8012            |            |
|                   | for Mean                            | Upper Bound | 12.9959            |            |
|                   | 5% Trimmed Mean                     |             | 12.3712            |            |
|                   | Median                              |             | 12.0000            |            |
|                   | Variance                            |             | 12.592             |            |
|                   | Std. Deviation                      |             | 3.54850            |            |
|                   | Minimum<br>Maximum                  |             | 5.00<br>20.00      |            |
|                   | Range                               |             | 15.00              |            |
|                   | Interquartile Range                 |             | 5.00               |            |
|                   | Skewness                            |             | .090               | .206       |
|                   | Kurtosis                            |             | 237                | .410       |
| SAM1_STRESS       | Mean                                |             | 10.3333            | .28951     |
|                   | 95% Confidence Interval<br>for Mean | Lower Bound | 9.7608             |            |
|                   |                                     | Upper Bound | 10.9058            |            |
|                   | 5% Trimmed Mean                     |             | 10.2101            |            |
|                   | Median                              |             | 10.0000            |            |
|                   | Std. Deviation                      |             | 11.567<br>3.40102  |            |
|                   | Std. Deviation<br>Minimum           |             | 4.00               |            |
|                   | Maximum                             |             | 20.00              |            |
|                   | Range                               |             | 16.00              |            |
|                   | Interquartile Range                 |             | 4.00               |            |
|                   | Skewness                            |             | .485               | .206       |
|                   | Kurtosis                            |             | .242               | .410       |

### **Tests of Normality**

|                                       | Kolm      | ogorov-Smi | rnov <sup>a</sup> | 5         | hapiro-Wilk |      |
|---------------------------------------|-----------|------------|-------------------|-----------|-------------|------|
|                                       | Statistic | df         | Sig.              | Statistic | df          | Sig. |
| SAM1_STRESS                           | .083      | 109        | .062              | .980      | 109         | .097 |
| SAM2_STRESS                           | .079      | 109        | .088              | .968      | 109         | .010 |
| a. Lilliefors Significance Correction |           |            |                   |           |             |      |

### **Paired Samples Statistics**

|        |             | Mean    | N   | Std.<br>Deviation | Std. Error<br>Mean |
|--------|-------------|---------|-----|-------------------|--------------------|
| Pair 1 | SAM1_STRESS | 10.7890 | 109 | 3.56182           | .34116             |
|        | SAM2_STRESS | 11.5229 | 109 | 4.40874           | .42228             |

### **Paired Samples Correlations**

|                                  | Ν   | Correlation | Sig. |  |
|----------------------------------|-----|-------------|------|--|
| Pair 1 SAM1_STRESS & SAM2_STRESS | 109 | .233        | .015 |  |

### **Paired Samples Test**

|        | Paired Differences           |       |                   |                    |                                   |        |        |     |                     |
|--------|------------------------------|-------|-------------------|--------------------|-----------------------------------|--------|--------|-----|---------------------|
|        |                              | Mean  | Std.<br>Deviation | Std. Error<br>Mean | 95% Confiden<br>the Diff<br>Lower |        | t      | df  | Sig. (2–<br>tailed) |
| Pair 1 | SAM1_STRESS -<br>SAM2_STRESS | 73394 | 4.98078           | .47707             | -1.67959                          | .21170 | -1.538 | 108 | .127                |

### Tests of Normality

|                         | Kolmo     | ogorov-Smir | rnov <sup>a</sup> | S         | hapiro-Wilk |      |
|-------------------------|-----------|-------------|-------------------|-----------|-------------|------|
|                         | Statistic | df          | Sig.              | Statistic | df          | Sig. |
| SAM1_CONTROL_SELF       | .095      | 138         | .004              | .961      | 138         | .001 |
| SAM1_THREAT             | .153      | 138         | .000              | .882      | 138         | .000 |
| SAM1_CENTRAL            | .074      | 138         | .058              | .964      | 138         | .001 |
| SAM1_UNCONTROL          | .099      | 138         | .002              | .951      | 138         | .000 |
| SAM1_CONTROL_OTHE<br>RS | .087      | 138         | .012              | .968      | 138         | .003 |
| SAM1_CHALLENGE          | .071      | 138         | .083              | .980      | 138         | .036 |
| SAM1_STRESS             | .097      | 138         | .003              | .972      | 138         | .007 |

a. Lilliefors Significance Correction

### Tests of Normality

|                          | Kolmogorov–Smirnov <sup>a</sup> |     |      | S         | hapiro-Wilk |      |
|--------------------------|---------------------------------|-----|------|-----------|-------------|------|
|                          | Statistic                       | df  | Sig. | Statistic | df          | Sig. |
| SAM1_CONTROL_SELF        | .093                            | 147 | .003 | .960      | 147         | .000 |
| a. Lilliefors Significan |                                 |     |      |           |             |      |

### **Tests of Normality**

| Statisti           | df    | Sig.  | Statistic | df  | C:   |
|--------------------|-------|-------|-----------|-----|------|
|                    |       | sig.  | Statistic | ar  | Sig. |
| SAM1_CHALLENGE .06 | 5 148 | .200* | .979      | 148 | .021 |

\*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

### Descriptives

|               |                         |                     | Statistic | Std. Error |  |
|---------------|-------------------------|---------------------|-----------|------------|--|
| Years in role | Mean                    | 2.1435              | .09194    |            |  |
|               | 95% Confidence Interval | Lower Bound         | 1.9623    |            |  |
|               | for Mean                | Upper Bound         | 2.3247    |            |  |
|               | 5% Trimmed Mean         | 2.0484              |           |            |  |
|               | Median                  | 2.0000              |           |            |  |
|               | Variance                | 1.826               |           |            |  |
|               | Std. Deviation          | 1.35123             |           |            |  |
|               | Minimum                 | 1.00                |           |            |  |
|               | Maximum                 | 5.00                |           |            |  |
|               | Range                   | 4.00                |           |            |  |
|               | Interquartile Range     | Interquartile Range |           |            |  |
|               | Skewness                |                     | .969      | .166       |  |
|               | Kurtosis                | 311                 | .330      |            |  |

### **Tests of Normality**

|               | Kolmogorov–Smirnov <sup>a</sup> |     |      | S         | hapiro-Wilk |      |  |  |  |  |
|---------------|---------------------------------|-----|------|-----------|-------------|------|--|--|--|--|
|               | Statistic                       | df  | Sig. | Statistic | df          | Sig. |  |  |  |  |
| Years in role | .255                            | 216 | .000 | .786      | 216         | .000 |  |  |  |  |
| 1.111. 6      |                                 |     |      |           |             |      |  |  |  |  |

a. Lilliefors Significance Correction

### Hypothesis Test Summary

|   | Null Hypothesis   | Test                                       | Sig. <sup>a,b</sup> | Decision                    |
|---|---|--|---------------------|-----------------------------|
| 1 | The distribution of DC_TOTAL<br>is the same across categories<br>of Screener. | Independent-Samples<br>Kruskal-Wallis Test | .001                | Reject the null hypothesis. |

a. The significance level is .050.

b. Asymptotic significance is displayed.

### Independent-Samples Kruskal-Wallis Test Summary

| Total N                       | 94                  |
|-------------------------------|---------------------|
| Test Statistic                | 19.002 <sup>a</sup> |
| Degree Of Freedom             | 4                   |
| Asymptotic Sig.(2-sided test) | .001                |

a. The test statistic is adjusted for ties.

### Hypothesis Test Summary

|   | Null Hypothesis  | Test                                       | Sig. <sup>a,b</sup> | Decision                    |
|---|--|--|---------------------|-----------------------------|
| 1 | The distribution of DC_TOTAL<br>is the same across categories<br>of Years in role. | Independent-Samples<br>Kruskal-Wallis Test | .339                | Retain the null hypothesis. |

a. The significance level is .050.

b. Asymptotic significance is displayed.

### Independent-Samples Kruskal-Wallis Test Summary

| Total N                       | 94                   |
|-------------------------------|----------------------|
| Test Statistic                | 4.532 <sup>a,b</sup> |
| Degree Of Freedom             | 4                    |
| Asymptotic Sig.(2-sided test) | .339                 |

a. The test statistic is adjusted for ties.

b. Multiple comparisons are not performed because the overall test does not show significant differences across samples.

### Independent Samples Test

|                |                                | Levene's Test<br>Varia |               |        |        |            |                          |            |          |       |
|----------------|--------------------------------|------------------------|---------------|--------|--------|------------|--------------------------|------------|----------|-------|
|                |                                |                        | Sig. (2- Mean |        | Mean   | Std. Error | 95% Confiden<br>the Diff |            |          |       |
|                |                                | F                      | Sig.          | t      | df     | tailed)    | Difference               | Difference | Lower    | Upper |
| SAM1_CHALLENGE | Equal variances<br>assumed     | .721                   | .397          | -3.265 | 146    | .001       | -2.24690                 | .68825     | -3.60713 | 88668 |
|                | Equal variances not<br>assumed |                        |               | -3.032 | 46.980 | .004       | -2.24690                 | .74115     | -3.73791 | 75589 |

### Hypothesis Test Summary

|   | Null Hypothesis   | Test  | Sig. <sup>a,b</sup> | Decision                    |
|---|---|---|---------------------|-----------------------------|
| 1 | The distribution of<br>SAM1_CONTROL_SELF is the<br>same across categories of<br>Trad_NonTrad. | Independent-Samples Mann-<br>Whitney U Test | .036                | Reject the null hypothesis. |

a. The significance level is .050.

b. Asymptotic significance is displayed.

### Independent-Samples Mann-Whitney U Test Summary

| Total N                        | 147      |
|--------------------------------|----------|
| Mann-Whitney U                 | 2237.000 |
| Wilcoxon W                     | 2733.000 |
| Test Statistic                 | 2237.000 |
| Standard Error                 | 209.790  |
| Standardized Test<br>Statistic | 2.093    |
| Asymptotic Sig.(2-sided test)  | .036     |

|                     |                           |                              | Co                   | rrelations        |                    |                   |                       |              |                   |                           |                         |                          |                         |                          |                        |                        |
|---------------------|---------------------------|------------------------------|----------------------|-------------------|--------------------|-------------------|-----------------------|--------------|-------------------|---------------------------|-------------------------|--------------------------|-------------------------|--------------------------|------------------------|------------------------|
|                     |                           | Death<br>Competency<br>Total | sam1_ctrl_se<br>lf_c | sam1_threat<br>_c | sam1_central<br>_c | sam1_unctrl_<br>c | sam1_ctrloth<br>ers_c | sam1_chall_c | sam1_stress<br>_c | sam1_inter_c<br>_ctrlself | sam1_inter_c<br>_threat | sam1_inter_c<br>_central | sam1_inter_c<br>_unctrl | sam1_inter_c<br>_ctrloth | sam1_inter_c<br>_chall | sam1_inter_<br>_stress |
| Pearson Correlation | Death Competency<br>Total | 1.000                        | .248                 | 050               | 058                | 080               | .084                  | .197         | 060               | .211                      | 064                     | 081                      | 027                     | .051                     | .142                   | 04                     |
|                     | sam1_ctrl_self_c          | .248                         | 1.000                | 462               | .000               | 193               | .550                  | .609         | 310               | .852                      | 338                     | .086                     | 149                     | .443                     | .550                   | 16                     |
|                     | sam1_threat_c             | 050                          | 462                  | 1.000             | .228               | .525              | 401                   | 162          | .739              | 322                       | .814                    | .200                     | .459                    | 280                      | 076                    | .57                    |
|                     | sam1_central_c            | 058                          | .000                 | .228              | 1.000              | .032              | 027                   | .294         | .544              | .080                      | .196                    | .845                     | .055                    | .013                     | .331                   | .48                    |
|                     | sam1_unctrl_c             | 080                          | 193                  | .525              | .032               | 1.000             | 363                   | 268          | .428              | 149                       | .492                    | .064                     | .872                    | 285                      | 112                    | .37                    |
|                     | sam1_ctrlothers_c         | .084                         | .550                 | 401               | 027                | 363               | 1.000                 | .531         | 203               | .467                      | 306                     | .025                     | 296                     | .892                     | .434                   | 11                     |
|                     | sam1_chall_c              | .197                         | .609                 | 162               | .294               | 268               | .531                  | 1.000        | .090              | .515                      | 080                     | .326                     | 109                     | .381                     | .812                   | .17                    |
|                     | sam1_stress_c             | 060                          | 310                  | .739              | .544               | .428              | 203                   | .090         | 1.000             | 168                       | .622                    | .523                     | .378                    | 113                      | .196                   | .879                   |
|                     | sam1_inter_c_ctrlself     | .211                         | .852                 | 322               | .080               | 149               | .467                  | .515         | 168               | 1.000                     | 395                     | .095                     | 171                     | .523                     | .642                   | 191                    |
|                     | sam1_inter_c_threat       | 064                          | 338                  | .814              | .196               | .492              | 306                   | 080          | .622              | 395                       | 1.000                   | .243                     | .565                    | 343                      | 095                    | .708                   |
|                     | sam1_inter_c_central      | 081                          | .086                 | .200              | .845               | .064              | .025                  | .326         | .523              | .095                      | .243                    | 1.000                    | .080                    | .027                     | .386                   | .591                   |
|                     | sam1_inter_c_unctrl       | 027                          | 149                  | .459              | .055               | .872              | 296                   | 109          | .378              | 171                       | .565                    | .080                     | 1.000                   | 332                      | 125                    | .432                   |
|                     | sam1_inter_c_ctrloth      | .051                         | .443                 | 280               | .013               | 285               | .892                  | .381         | 113               | .523                      | 343                     | .027                     | 332                     | 1.000                    | .486                   | 126                    |
|                     | sam1_inter_c_chall        | .142                         | .550                 | 076               | .331               | 112               | .434                  | .812         | .196              | .642                      | 095                     | .386                     | 125                     | .486                     | 1.000                  | .220                   |
|                     | sam1_inter_c_stress       | 040                          | 163                  | .577              | .487               | .376              | 113                   | .175         | .879              | 191                       | .708                    | .591                     | .432                    | 126                      | .220                   | 1.000                  |
| Sig. (1-tailed)     | Death Competency<br>Total |                              | .011                 | .325              | .299               | .236              | .223                  | .036         | .294              | .027                      | .282                    | .232                     | .404                    | .322                     | .099                   | .360                   |
|                     | sam1_ctrl_self_c          | .011                         |                      | .000              | .499               | .040              | .000                  | .000         | .002              | .000                      | .001                    | .219                     | .088                    | .000                     | .000                   | .069                   |
|                     | sam1_threat_c             | .325                         | .000                 |                   | .018               | .000              | .000                  | .070         | .000              | .001                      | .000                    | .034                     | .000                    | .005                     | .247                   | .000                   |
|                     | sam1_central_c            | .299                         | .499                 | .018              |                    | .387              | .405                  | .003         | .000              | .235                      | .037                    | .000                     | .310                    | .454                     | .001                   | .000                   |
|                     | sam1_unctrl_c             | .236                         | .040                 | .000              | .387               |                   | .000                  | .007         | .000              | .088                      | .000                    | .282                     | .000                    | .004                     | .156                   | .000                   |
|                     | sam1_ctrlothers_c         | .223                         | .000                 | .000              | .405               | .000              |                       | .000         | .032              | .000                      | .002                    | .412                     | .003                    | .000                     | .000                   | .154                   |
|                     | sam1_chall_c              | .036                         | .000                 | .070              | .003               | .007              | .000                  |              | .208              | .000                      | .235                    | .001                     | .161                    | .000                     | .000                   | .056                   |
|                     | sam1_stress_c             | .294                         | .002                 | .000              | .000               | .000              | .032                  | .208         |                   | .064                      | .000                    | .000                     | .000                    | .154                     | .037                   | .000                   |
|                     | sam1_inter_c_ctriself     | .027                         | .000                 | .001              | .235               | .088              | .000                  | .000         | .064              |                           | .000                    | .195                     | .059                    | .000                     | .000                   | .041                   |
|                     | sam1_inter_c_threat       | .282                         | .001                 | .000              | .037               | .000              | .002                  | .235         | .000              | .000                      |                         | .013                     | .000                    | .001                     | .196                   | .000                   |
|                     | sam1_inter_c_central      | .232                         | .219                 | .034              | .000               | .282              | .412                  | .001         | .000              | .195                      | .013                    |                          | .235                    | .404                     | .000                   | .000                   |
|                     | sam1_inter_c_unctrl       | .404                         | .088                 | .000              | .310               | .000              | .003                  | .161         | .000              | .059                      | .000                    | .235                     |                         | .001                     | .130                   | .000                   |
|                     | sam1_inter_c_ctrloth      | .322                         | .000                 | .005              | .454               | .004              | .000                  | .000         | .154              | .000                      | .001                    | .404                     | .001                    |                          | .000                   | .127                   |
|                     | sam1_inter_c_chall        | .099                         | .000                 | .247              | .001               | .156              | .000                  | .000         | .037              | .000                      | .196                    | .000                     | .130                    | .000                     |                        | .022                   |
|                     | sam1_inter_c_stress       | .360                         | .069                 | .000              | .000               | .000              | .154                  | .056         | .000              | .041                      | .000                    | .000                     | .000                    | .127                     | .022                   |                        |
| N                   | Death Competency<br>Total | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_ctrl_self_c          | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_threat_c             | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_central_c            | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_unctrl_c             | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_ctriothers_c         | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_chall_c              | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_stress_c             | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_inter_c_ctriself     | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_inter_c_threat       | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_inter_c_central      | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_inter_c_unctrl       | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_inter_c_ctrloth      | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_inter_c_chall        | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |
|                     | sam1_inter_c_stress       | 84                           | 84                   | 84                | 84                 | 84                | 84                    | 84           | 84                | 84                        | 84                      | 84                       | 84                      | 84                       | 84                     | 84                     |

### Variables Entered/Removed<sup>a</sup>

| Model | Variables<br>Entered   | Variables<br>Removed | Method |
|-------|--|----------------------|--------|
| 1     | sam1_stress<br>_C,<br>sam1_unctrl_<br>c,<br>sam1_ctrloth<br>ers_C,<br>sam1_ctrloth<br>_C,<br>sam1_ctrl_se<br>lf_c,<br>sam1_threat<br>_c  |                      | Enter  |
| 2     | sam1_inter_c<br>_threat,<br>sam1_inter_c<br>_chall,<br>sam1_inter_c<br>_central,<br>sam1_inter_c<br>_unttrl,<br>sam1_inter_c<br>_ttrlself,<br>sam1_inter_c<br>_ttrlself,<br>_sam1_inter_c<br>_ttrloth,<br>_sam1_inter_c<br>_stress |                      | Enter  |

a. Dependent Variable: Death Competency Total

b. All requested variables entered.

### Model Summary<sup>c</sup>

|       |                   |          |                      |                            | Change Statistics  |          |     |     |               |                   |
|-------|-------------------|----------|----------------------|----------------------------|--------------------|----------|-----|-----|---------------|-------------------|
| Model | R                 | R Square | Adjusted R<br>Square | Std. Error of the Estimate | R Square<br>Change | F Change | df1 | df2 | Sig. F Change | Durbin-<br>Watson |
| 1     | .305 <sup>a</sup> | .093     | .009                 | 18.58199                   | .093               | 1.111    | 7   | 76  | .365          |                   |
| 2     | .347 <sup>b</sup> | .121     | 058                  | 19.19992                   | .028               | .312     | 7   | 69  | .946          | 2.063             |

a. Predictors: (Constant), sam1\_stress\_c, sam1\_chall\_c, sam1\_unctrl\_c, sam1\_ctrlothers\_c, sam1\_central\_c, sam1\_ctrl\_self\_c, sam1\_threat\_c b. Predictors: (Constant), sam1\_stress\_c, sam1\_chall\_c, sam1\_unctrl\_c, sam1\_ctrlothers\_c, sam1\_central\_c, sam1\_ctrl\_self\_c, sam1\_threat\_c, sam1\_inter\_c\_threat, sam1\_inter\_c\_chall, sam1\_inter\_c\_central, sam1\_inter\_c\_unctrl, sam1\_inter\_c\_ctrlself, sam1\_inter\_c\_ctrloth, sam1\_inter\_c\_stress

c. Dependent Variable: Death Competency Total