



**Exploration of the Psychological Factors Impacting Confidence in,  
and Comfort with, the Delivery of End-of-Life Care.**

John Latham  
Doctorate in Clinical Psychology

Supervised by:  
Dr. Sarah Butchard  
Dr. Stephen Mason

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### **Word Counts**

Systematic Review: 6,383 (Excluding Title Page, Abstract, References, Figures, and Tables)

Empirical Paper: 7,392 (Excluding Title Page, Abstract, References, Figures, and Tables)



*“Death is among us. To see it always and only as a negative subject is to lose sight of its power to enhance every moment.*

*Just as we are often unable to speak about our need to love and be loved because we fear our words would be interpreted as signs of weakness or failure, so are we rarely able to share our thoughts about death and dying.”*

*- bell hooks [sic], All About Love, p200*

## Chapter 1: Introduction and Overview

### An Introduction

#### *The Universal Nature of Fear, and Death*

Fear and death are two human experiences that appear to be well recognised across cultures and time periods. Some of the earliest known writings refer to fear and, from what can be identified thus far, all also refer to death in some form (Ariès, 1975; Budge, 2019; Solomon, 2003). Both fear and death can be found in these texts separately, describing distinct concepts, but they can also be found together, describing fears that emerge from an encounter with, or anticipation of, death. Freud drew from the early Greek mythos of Eros and Thanatos, to formulate his understanding of how death is unconsciously processed into a drive that motivates the internal jostle between self-destruction and self-creation (Lind, 1991). Texts from the Middle Ages indicate a period of evolution in how death was understood, shifting it from a somewhat neutral life cycle event within a community, toward it being a point of personal and spiritual significance (Ariès, 1975). Even cultures that express familiarity and a sense of celebration when describing the subject of death, for example the ancient Egyptians in their depictions of, preparations for, and transitions through, death, also shared fears related to death, and fears related to working with death, in the Book of the Dead (Budge, 2019), Pyramid Texts (Mercer, 2020) and Coffin Texts (Eicke, 2017).

Social context, as recorded through historical texts, offers a picture of how social processing can impact the emotional experience of events surrounding death and dying. For ancient

Egyptians, fears related to accountability to the gods, and the legacy and memory of an individual or family name, led to a heightened sensitivity, or fear, of failure connected with death (Eicke, 2017). Delumeau explored the way in which Judaeo-Christian beliefs shaped how fear, often linked to death, was constructed over many centuries to motivate personal responsibility, and used as a tool of discipline and punishment (Bornstein, 1994). For example, he suggested that death through disease contagion, which grew with the development and integration of cultures and communities across the globe during the period of the Roman Empire and beyond, was presented in some religious texts as a method of God's judgement of people. As degeneration replaced contagion as the main source of mortality, the western cultural narrative shifted from a fear of otherness to a fear of the unseen forces at work in the deterioration of the human body (Bornstein, 1994; Stearns, 2006).

From this brief historical snapshot, one can observe how societal and cultural factors impact the interpretation of fear and death. Indeed, whilst fear has clear biological components, presented by evolutionists as core to human protection and survival (Festinger, 1954; Öhman, 2009; Schoenberger, Kirsch, & Rosengard, 1991), social processing seems essential to how fears become linked with death, through the perception, identification, and evaluation of these experiences. When social processing, and subsequent social comparison, are combined with these concepts, additional variations of emotion are suggested to develop; for example, emotions like envy, judgement, guilt, regret, defensiveness, success, and failure (Eicke, 2017; White et al., 2006).

The words fear and death, when combined, are most associated with the experience of reflecting on one's personal mortality. From this, studies have emerged exploring the emotion of death anxiety and its impact on personal and professional behaviours (Draper et al., 2019; Izard, 2010). However, there is the lesser considered relationship with death and dying: the impact of working with people who are dying and, for those who are designated as 'healers' within modern medical settings, like doctors and nurses, how it may activate underlying fears not just about personal mortality, but also about one's own sense of self and value.

This thesis aims to firstly introduce the reader to the emotional experiences of clinicians working with end-of-life (EOL) patients, focusing not on emotions connected to personal mortality, but rather on other lesser considered emotions that emerge. Secondly, it explores a specific emotional concept – Fear of Failure – and how this fear may impact effective delivery of clinical care with dying patients.

Several terms are used interchangeably in this thesis to describe EOL 'care'. These include reference to EOL 'conversations', EOL 'communication', EOL 'decision-making', EOL 'working', EOL 'experience', EOL 'education' and EOL 'intervention'. The term 'care' is broad because it describes a full process that may span time, as well as different interventions, clinical teams, and specialisms. To offer good quality EOL care, is to deliver support that is patient centred, proactive, and based on up-to-date training and knowledge. It has patient need at the centre, meaning that the patient knows what is happening within their body and what their treatment options are, because of clear, accurate, and unobstructed communication from a trained and appropriate clinician. It means that when patients make

an informed decision about what treatment they want, they have the requisite information, are listened to, and they receive the care needed because of effective team working and decision-making. Within this thesis, it is the intention to refer to the full broad process of EOL care, using this general term. Where this is not possible, for example referring to literature discussing specific elements of the EOL care process, the thesis will name the specific elements being explored.

## **Thesis Overview**

### ***Developing a Research Direction***

This research project developed from discussions within palliative care teams at two NHS hospitals in the North East and North West England. Numerous studies had pointed toward a lack of education and guidance as the cause of ineffective EOL care, namely deficits in communication and decision making and, as a result, resources had been directed towards education programmes for medical teams in hospitals. However, palliative care teams reported that, despite these additional resources and courses increasing competence, non-palliative care clinicians were still reluctant to have effective EOL conversations and were delaying important medical decisions for people at the EOL. It was concluded that it was likely that there were other factors acting as barriers to working effectively with EOL patients.

Firstly, we identified that very little research had been completed exploring whether psychological factors affected the delivery of EOL care. We found that only Death Anxiety, a concept that had been proposed in the mid-1980s as one possible factor impacting upon clinical practice (Langs & Giovacchini, 2018), had been thoroughly investigated. In 2019, a

systematic review explored the existing literature to identify whether Death Anxiety could be found to have a direct psychological impact on medical practice (Draper et al., 2019). As is discussed in the introduction of Chapter 3 (the empirical paper within this thesis), the systematic review was unable to report conclusively that Death Anxiety was the major psychological process impacting communication and decision-making by medical professionals at the EOL. During communication with the authors of the review, it was agreed that it was likely that other/additional psychological factors, outside of Death Anxiety, impacted clinical practice with dying patients.

### ***The Systematic Review: Chapter 2***

Drawing together the conversations with professionals working in palliative care teams and settings, and with the authors of the aforementioned systematic review, it was decided that it was firstly important to determine whether emotions experienced by clinicians working with those at the EOL had been identified in research studies. It was believed that investigating emotions would offer a unique insight into how physicians experience care of the dying and would act as a springboard for further exploration. Following a scoping review, we acknowledged that it was largely qualitative studies that had identified clinician emotions, although these were rarely research projects designed explicitly for this purpose, and emotions were most often passively captured in quotes to illustrate other phenomena. Therefore, a systematic review that stripped back existing qualitative studies, identifying any emotions named or alluded to in presented quotes and researcher-generated themes, would be a valuable contribution to this field. The systematic review in Chapter 2 of this thesis was developed from this perspective. It is worth noting that the systematic review has included papers that have reported emotions post-death as

well as pre-death (during EOL care). This was because it became clear in the review process, and in consultation with supervisors, that many emotions experienced throughout the EOL care process may only present themselves once the 'process', in the mind of the clinician, is complete; for example, once a body has been removed from a ward, or when a clinician is at home and reflects on their day. Further examination of this 'emotion-mind lag' is merited, but not considered within the scope of this thesis.

In advance of thesis submission, this systematic review has been reviewed and published by the British Medical Journal: Supportive and Palliative Care (Available at: Latham JS, Butchard S, Mason SR. BMJ Supportive & Palliative Care, Epub ahead of print: 21-04-22. doi:10.1136/bmjspcare-2021-003446).

### ***The Empirical Research: Chapter 3***

Fear, failure, and social expectation were three factors drawn from the themes identified in the systematic review. Similarly, palliative care colleagues considered these factors key to what they observed as hesitancy when delivering EOL information to patients, families, and colleagues. It was decided that these themes would be a useful starting point for the exploration of psychological factors impacting upon the care of EOL patients.

Therefore, the empirical paper in Chapter 3 of this thesis uses a questionnaire design to identify the role Fear of Failure (FOF) may have on a person's sense of self efficacy when delivering EOL care, focusing on their perceived confidence in EOL communication, working with other teams regarding EOL issues, and EOL decision-making, and their overall comfortableness with EOL care. The paper is currently in peer review with the BMC Medical Education Journal.

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## **Chapter 2: Systematic Review**

### **The Emotional Experience of End-of-Life Communication and Decision-Making for Physicians: A Systematic Review of Qualitative Studies**

As prepared for BMJ Supportive and Palliative Care, with the reference style changed from Vancouver to an APA format for the purposes of thesis continuity. Author guidelines for this journal can be found here: <https://spcare.bmj.com/pages/authors/#review>

The manuscript has been adapted from the published format in some parts to provide further context.

#### **Key Words**

Physician, death, end-of-life, communication, decision-making, emotions, thematic synthesis

#### **Acknowledgements Specific to this Systematic Review**

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## **Abstract**

### **Objective**

To explore the emotional experience of physicians in acute settings when encountering end-of-life conversations and decision making.

### **Method**

Thematic Synthesis of qualitative studies. Medline, PsycINFO, PubMed, BNI, and CIAHL were searched from 1985 to 2021 for studies published in English. Data extraction was informed by a framework created for assessing methodological quality by Polanin, Pigott, Espelage, & Grotzinger (2019) and adapted by Draper et al. (2019).

### **Results**

Of 8429 papers identified, 17 were selected for review. Two themes containing 10 sub-themes described the emotional and psychological factors impacting the experience of end-of-life care, namely: a tension between desire and ability to communicate end-of-life news, and a conflict of hiding versus revealing self across several practical and emotional contexts.

### **Conclusion**

Medical training is only a minor factor influencing how well a person copes with end-of-life care and may sometimes feed negative appraisals. Lack of support from senior colleagues, fear of criticism and a sense of perceived failure were linked to lower self-efficacy in end-of-life care. Beyond learning practical skills, physicians benefit from understanding the psychological factors impacting their experience and in building self-efficacy and observing senior colleagues processing strong and difficult emotions effectively.

**Clinical Implications**

Promoting personal reflection and sharing of the experiences encountered in end-of-life care, especially modelled from senior colleagues, may contribute to improvements in competence and reduce the impact of heroism, feelings of failure, and avoidance in practice.

## Introduction

### **The Emotional Experience of Working with End-of-Life Patients**

Exposure to death and dying in an acute care setting can lead to healthcare workers experiencing grief, depression, anxiety, burnout, and stress (Kearney et al., 2009; Sorensen & Ledema, 2009). It has also been found to prompt constructive reflection, and thus be rewarding and a source of personal growth (Aase, Nordrehaug, & Malterud, 2008). How death is emotionally experienced in clinical roles has been shown to impact coping strategies, decision-making and professional and personal relationships (Ledema et al., 2004).

For physicians, although the expectation is that they will cope with the emotional demands of their workplace (Zambrano, Chur-Hansen, & Crawford, 2012) the specific emotional impact is rarely explored (Guest et al., 2011). Understanding the emotional experience of physicians working with death is important in developing relevant and effective support, education, and resources for this population (Kozlik, Neumann, & Lozo, 2015).

Currently, no systematic review exists that draws together the emotional experiences of physicians providing end-of-life (EOL) care. This systematic review aims to review qualitative literature looking at physicians working with EOL patients in acute healthcare settings, with the purpose of drawing out themes related to their emotional experience of working with this patient group.

## Developing the Research

In acute care settings, where rapid problem-solving in crisis situations is required, physicians ultimately have the duty of clinical care within the wider clinical team, meaning they will largely be responsible for communicating and making decisions. These settings are an often-overlooked pathway of EOL care, and this was an area of concern highlighted during the Covid-19 pandemic when physicians with nonpalliative backgrounds were being required to have more EOL responsibility (Kim, 2020). Although there is a move to integrate palliative care within other specialties, data indicates that this is limited and inconsistent across the NHS, often leaving a gap between physicians providing curative treatment and those offering supportive and palliative care (Gajra, 2021; NICE, 2019).

By exploring qualitative studies from this area, this research will look for identified perceptions and emotions brought up by these EOL experiences and may be able to observe patterns linking these emotions to psychological process and behaviours known to be barriers to effective care. Whilst national clinical guidance encourages physicians to recognise that personal views, values, and feelings affect communication and decision making, both on the part of the physician and the patient (General Medical Council, 2020), there has been an identified bias in medical education toward a scientific 'positivist' and reductionist approach to medical intervention (Mann, Dornan, & Teunissen, 2011). The Francis Report Inquiry (2013) suggested that medical education has often been ineffective in developing in physicians the skills to adequately provide holistic and compassionate care to patients, and instead focusses on treatment. Studies of cognitive processes in physicians have shown that it is important that physicians consider the role emotions play in their own

practice, as well as in how they show compassion to their patients. Emotions have been found to strongly influence the styles and strategies physicians use to guide diagnosis and treatment, with negative emotions reducing a physician's ability to process complex problems effectively (Ofri, 2013). Emotions activated indicating a potential threat, such as fear, envy, judgement, guilt, regret, defensiveness, and failure (White et al., 2006) are known to be detrimental to patient care (Balch & Copeland, 2007). This includes a poorer response to feedback (Latham & Locke, 2018), and diminished desire and motivation to meet performance targets (Burg et al., 2017). Negative emotional experience has also been shown to have a compounding effect, becoming cyclical, impairing further efforts to motivate and achieve additional goals, or motivate others to achieve personal or professional goals (Caraway et al., 2003).

Understanding experienced emotions has been found to be a reliable predictor of approach-avoidance behaviours, the adaptive emotional and physiological response of moving toward positive and affirmative stimuli, or away from stimuli that are perceived as potentially harmful to sense of self or person, compared with other principles of motivation (Kozlik, Neumann, & Lozo, 2015).

Given this research's theoretical stance that emotion is likely to be a construct of social interaction, and observation and reinforcement of and from social systems, and given the complexity of the hospital care environment, it was decided that qualitative studies that had interviewed physicians were more likely to offer an insight into the context of an experience of emotion. Qualitative studies also have additional benefit in that they sometimes offer a discussion related to non-verbal responses from participants, or comment on changes in

participant behaviour, such as a reluctance to address a topic or question. These additional insights would be useful in constructing an accurate and broad review of the field.

The Research Case Report (Royal College of Physicians, 2019) outlined the growing benefits of in-practice research. Whilst clinicians are encouraged to develop research in their clinical areas, those who are given protected research time are often drawn toward research that contains performance metrics or follows a method with which the clinician is already familiar (Al-Busaidi, 2008; Altman, 1994). Perhaps due to the demand on clinicians' time (Khalaf et al., 2019; Masic, Miokovic, & Muhamedagic, 2008), the risk of exposure or litigation (Dadipoor et al., 2019; Siddiqui et al., 2022), or simply a synergetic draw to quantitative research that is data-driven, structured, and formulaic, acute care clinicians are not quick to develop and engage in qualitative studies (Jacob, 2016), and this leaves their voice somewhat neglected in the research. Further, feeling and describing emotional experience is not something that was traditionally promoted within medical education, and given that anger, fear, and intimidation may be some of the dominant emotions historically expressed within trainer-trainee relationships (Crowe, Clarke, & Brugha, 2017), emotion may not be something that feels safe to explore. By reviewing qualitative studies that have explored physician experience in acute care settings, one can offer a platform for their voices within the research and generate a dialogue about shared themes of feelings and experience.

## **Research Aims**



This systemic review aims to identify and synthesise the existing literature in relation to physicians' emotional experience of providing EOL care in acute care settings. Specifically, it will:

- Examine qualitative studies that have interviewed physicians in acute settings and have identified the emotional experience of EOL care.
- Utilise Thematic Synthesis to draw together the emotions identified and their links to EOL care practices.
- Build an understanding of how the emotional experiences of physicians providing EOL care impacts both positively and negatively on care practices.

## Method

A protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO; CRD42021238775), and the paper written in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting guidelines (Page, McKenzie, Bossuyt et al., 2020). No pre-existing systematic reviews exploring physicians' emotional experience in end-of-life care were identified in provisional literature searches, PROSPERO database or Cochrane Library searches.

### Search Strategy

Search terms were formulated using the Population, Intervention, Comparison and Outcomes tool (PICO; Methley, Campbell, Chew-Graham et al., 2014; Table 1). Medline, PsycINFO, PubMed, BNI, and CIAHL were searched from 1985 to 2021 for studies published in English. Full search strategy can be found in supplementary materials under Appendix A.

**Table 1**

#### *PICO Tool and Search Terms*

PICO Domain		Criteria	Search terms
P	Population	Physicians	"(((Physician* OR physician* OR "specialist nurs*").ti,ab AND ("end of life" OR palliative).ti,ab) AND (conversation* OR communicat* OR decision*).ti,ab) AND (perspective* OR perception* OR attitude* OR view* OR approach* OR belief* OR opinion*).ti,ab"
I	Phenomenon of interest	Emotional experience of having EOL conversations and making EOL decisions	
Co	Context	Acute hospitals; working with patients at EOL.	

## Eligibility Criteria

Eligible were original studies, written in English, primarily communicating the views and experiences of physicians in at least their first year of practice, who have had EOL conversations, and refer to their perceptions and emotions of, including 'attitudes' towards, EOL care and the impact on medical communication with their colleagues, patients and/or medical decision-making, in adult (including older adult) acute populations. Only qualitative studies were considered. Case reports were included if they made explicit reference to emotions experienced. Papers that also recorded medical student perspectives were included if the study primarily reported qualified physician experience. Eligible studies were included irrespective of the definition of 'end-of life' used, although this has been captured in the analysis to give context to reviewed studies, and irrespective of the definitions used for emotions, perspectives, or experiences.

Excluded were quantitative studies, unless they included a significant free-text element allowing a participant to add their own words and perspective and that had been qualitatively analysed by the researchers. Also excluded were systematic reviews, background articles or commentaries, conference abstracts, guidance, or unpublished papers. All papers that were not focused explicitly on the experience and perspective of physicians (or medical students if included within papers primarily reporting on qualified physicians) were excluded. Also excluded were paediatric physicians, studies in non-acute settings like GP surgeries/community settings/home treatment, studies in settings like hospices, where treatment is knowingly palliative at the point of admission, and studies that reviewed the perspectives of professionals working with medically assisted dying. Also excluded were studies that did not capture the view of the clinician, for example the view of

the patient in relation to a clinician. Papers published before January 1985, as guided by Draper et al. (2019), may not reflect the current training and guidance offered to active clinicians and were therefore also excluded.

Also excluded were studies specifically looking at the experience of physicians in USA healthcare settings because of the unique influence of market forces on the delivery of EOL care in the USA. This decision was supported by research indicating that different hospital administration models in the US health system impact how income is generated from treatment (Cassell et al., 2003; Hofmann, 1992; Kaufman, 2005), how insurers may influence treatment decisions, (Whaley et al., 2020), how the unregulated cost of pharmaceuticals may impact decision-making for both clinician and patient (Yong, Saunders, & Olsen, 2010), and the role of industry lobbying on individual, local and national decision-making (Boivin et al., 2015; Jodice, 2020). Although other countries do involve insurance companies and are impacted by some market forces in the delivery of healthcare, countries outside the USA heavily regulate wealth disparity (Mitonga & Shilunga, 2020). Conversely, in the USA healthcare system, the share of health-care resources devoted to care of the wealthy has risen over time and the life expectancy of the wealthiest Americans now exceeds that of the poorest by 10–15 years (Dickman, Himmelstein & Woolhandler, 2017). Studies from USA that met all other inclusion criteria have been included in Appendix B but were not considered in the final review.

### **Study Selection**

The initial search yielded 8,429 articles. 4,143 duplicates were excluded, and the remaining studies were screened by title and abstract applying inclusion/exclusion criteria

using Rayyan, an online extraction and review software platform, leaving 154 for full review using the software Endnote X9 (see Figure H1; Appendix H). A 10% sample of stage two and the final papers were reviewed by the author's supervisor against the selection criteria. Following thorough written and verbal discussion with the supervising team there was inter-rater reliability for 100% of the sample, and 17 papers were included in the qualitative synthesis.

### **Quality Assessment**

Quality assessment was informed by a framework created by Polanin et al. (2019) and adapted by Draper et al. (2019). It also included review questions taken from the Clinical Appraisal Skills Programme Qualitative Checklist (CASP; Critical Appraisal Skills Programme, 2019) with a total score calculated to help inform assessment. Each paper was then reviewed against the Consolidated Criteria for Reporting Qualitative Research (COREQ) gold standard (Tong, Sainsbury & Craig, 2007) to determine the integrity of the studies. The checklists can be found in Appendix C.

### **Data Extraction and Synthesis**

All 17 full-text articles were imported into QSR's NVIVO 13 to extract final themes and synthesise narratives.

There were two key stages to synthesising the data. Firstly, a rudimentary content analysis was performed to familiarise the author with the data and context. NVIVO facilitated a word frequency search, followed by key word search specifically for emotions and associated words. The author considered each of the words in relation to the context of the text from

which the word was drawn and excluded words if the meaning of that word in the context was not explicitly related to feelings or emotions experienced. This list of emotions was grouped against pre-existing theories of emotions by Robinson (2008), and Sacharin, Schlegel & Scherer (2012), in order to make sense of the data and as a platform for building themes (Appendix F).

Secondly, steps 2 to 5, which include coding, generating themes, reviewing themes, defining, and naming themes were based on the Thematic Synthesis approach developed by Thomas and Harden (2008). Thematic Synthesis was used in order to preserve and respect the context and complexity of the themes identified in each study reviewed, whilst also drawing out new, broader themes to identify links across the literature.

Descriptive themes were developed by coding individual sentences that named or alluded to specific emotions, to stay close to the context of the primary studies. Most sentences identified had several codes applied to them. It was considered important to include the original author's own commentary and subthemes if they named emotions, as emotions may be non-verbal, and this would only be known by the authors conducting interviews and coding the transcriptions. Codes were either emotions, responses to emotions, situations that elicited emotions, or perceptions by physicians about emotions elicited or avoided. Next, codes were amalgamated between studies, and grouped into a hierarchical structure (Appendix F). Broad analytical themes and hypotheses were generated from these descriptions, in discussion with supervisors.

As identified by Thomas and Harden (2008) this approach allows the reviewer to consider in the analysis more than just participant speech and language. It also allows the reviewer to take account of the implied subtext and wider context, as described by authors of primary studies. This can include references about a participant's change in tone or speech pattern or shifts in body language as the participant describes their experience. While the development of descriptive themes remains 'close' to the primary studies, the analytical comments represent purposeful interpretation that generates new interpretive constructs, explanations, or hypotheses where appropriate. An example of how text from source papers has contributed to theme generation and analysis has been included in Appendix G.

The theoretical framework held by the reviewer that will be guiding elements of this analysis draw from the social constructivist theory that emotion is rooted in the perception of context, identity, and power relations (Averill, 1980). Therefore, as both self and other are active in the construction of meaning, identified emotions were considered within their context, and themes and subthemes were discussed and evaluated by the research team in terms of how descriptions described wider intra-personal social processes.

### **Reflexive Statement**

I acknowledge that researcher bias must be recognised in the development, synthesis, and interpretation of qualitative research for systematic review. Further, in bringing qualitative studies together, I recognise that this process will have de-contextualised findings and may make assumptions about comparability. As a Trainee Clinical Psychologist, I acknowledge that, despite applying several frameworks and methods to my data synthesis, I will also be bringing my own experiences into my interpretation. My

position on EOL is likely to be influenced by how death has impacted me and my family. This includes the death of my brother and other close relatives, but also as my father was a church minister, I grew up familiar with funerals and a religious understanding of death. These experiences are all likely to have influenced how life, death and grief were acknowledged, and sometimes not acknowledged, within my family growing up. I also recognise that my curiosity in this research field is at odds with the reluctance others may feel when discussing or experiencing the effects of death and loss. Attempts were made to enhance objectivity, including working in placements and with supervisors who could describe the broad range of emotions they had encountered in working with people at the EOL, and the processes around dying within an acute care setting.



## Results

Seventeen papers were included for analysis. The characteristics of the included studies are presented in Table E1 (Appendix E) and Key Findings in Table 2. The populations and settings were broad, ranging from hospitals in South America (n=1), Europe (n=9), Australasia (n=5), and North America (Canada; n=2), and included participants with a diverse level of professional experience, from junior physicians in first year of practice up to 47 years of practice. The perspectives of 348 physicians were captured, with a range between 8 to 96 across the papers. The majority of physicians interviewed were from Australasia (n=166), followed by Europe (n=145), Canada (n=25), and South America (n=12). Named specialties of participants included physicians from intensive care, oncology, haematology, geriatric medicine, palliative medicine, general medicine, intensive care, surgery, renal medicine, respiratory medicine, cardiology, and a pain specialist. One study captured data related to the training participants had had in palliative care and EOL communication (Economos, Bonneville-Levard, Djebari et al., 2020). It reported that all physicians interviewed over the age of 40, which was 5 out of 18 participants, reported never having received training in palliative care. Only one study reported the ethnicity of participants, and all were reported as Caucasian (Whitehead, 2012).

### Evaluation of Quality

Many of the papers reviewed lacked rigour. A quality percentage score was given for each included paper and is shown in Appendix D, based on the Critical Appraisal Skills Programme (2019; Appendix C). The author also completed a supplementary test of quality using the COREQ gold standard, which offers a more detailed framework for quality review (Tong et al., 2007; Appendix C). Based on these two quality assessments, it was identified

that many of the papers reviewed neglected to describe or consider any relationship between research and participant, if/what the researcher's biases may be, or how the recruitment strategy was developed. Beyond including ethics committees, many papers also did not clarify whether ethical issues had been taken into consideration, and whether psychological support was offered to participants following discussions about death, dying, grief and bereavement – especially when themes around feeling isolated, or the long-term consequences of unresolved grief or trauma were identified. Several papers did not describe the analysis process or how they developed their themes, making it difficult to directly compare methods and outcomes. Therefore, the papers represented a heterogeneous body of low-level evidence.

Table E1 (Appendix E) presents the characteristics of the seventeen included studies.

Table 2

## Key Findings of the Seventeen Qualitative Papers Analysed

Authors (year, country, paper title)	Relevant findings	Emotions experienced by Physicians named in study	Quality assessment in %age of total	Limitations
Amati, R. and Hannawa, A. F. (2014, Switzerland) Relational dialectics theory: Disentangling physician-perceived tensions of end-of-life communication	Five dialectical tensions and two new contradictions to Relational Dialectics Theory that are unique in the context of end-of-life care. Hierarchical structures are a particularly challenging barrier during end-of-life communication: struggle between dominating versus submitting themselves to the patient during end-of-life interactions. None of the participants was able to talk about "private" dialectical struggles without mentioning the patients or their family members, confirming that dialectical contradictions arise and develop within interactions. Illustrated a gap of differential perspectives between physicians, patients, and their families.	Detachment, forced to connect, closeness, close yourself off, when feeling good get more into the relationship, blocked and closed, issue with truth telling, close oneself, fragile, personal crisis, peaceful, survival, pressure, hide behind numbers, whirlwind of emotions and rationality, need for detachment, feeling torn between identifying and detachment, ambivalence, avoiding certain words, voicing or repressing, emotional burden, reminding of past experiences, silence feels heavy, not being able to say goodbye, hard to find the right words, staying on the surface, knowing they don't want to know - terribly hard, desire to save patients, feeling powerless, hard to explain, needing certainty, uncertainty, difficult to communicate uncertainty, dominance, knowing what they don't know - extremely tough.	60%	Focused on pre-existing theory – could have excluded / discounted evidence based on this theory.
Corradi, M. L. G., Duim, E. and Rodrigues, C. I. S. (2020, Brazil) Death and End of Life: Perceptions Throughout the Career About Death, Palliative Care, and Educational Process	Three main themes: (1) Negative feelings, perceptions, and experiences about death and EOL; (2) the importance of knowledge and training in palliative care; (3) Gaps in curricular structure hindering preparedness for palliative care and EOL communication.	Difficulties in defining death, strangeness, discomfort, sadness and pain, anguish, impotence, frustration, insecurity, and sometimes apathy. Speech markers included surprise, choking up and long pauses. Move outside comfort zone, appeared insecure, evidenced a lack of interest, stirs bad feelings, feeling of helplessness, difficulty, I feel pain, fear, anxiety, uncertainties, reassurance. Unprepared, uncomfortable with caring for the naturally sick at the EOL.	70%	Did not explain the sampling or analysis strategy or about the author's influence in much detail.
Crawford, G. B. and Zambrano, S. C. (2015, Australia) Junior Physicians' views of how their undergraduate clinical electives in palliative care influenced their current practice of medicine	Two main themes: (1) from apprehension to gaining a sense of control, and (2) gaining perspective on the practice of medicine. Participants perceived that the learning experiences from the attachments provided them with a sense of confidence and control over their interactions with dying patients and families.	From apprehension to gaining a sense of control, gaining perspective, self-awareness, learning about coping, feelings of vulnerability, fear of making mistakes, feeling like they've learned skills, sense of self-confidence, feeling useful, feeling in control, difficult and emotionally laden, getting too attached, feeling more emotionally prepared, allowed them to explore their emotional reactions, importance of coping, self-awareness, went home and cried to mum, complex issues being brushed over by others more senior, everyone wants to fix the problem, focus on accepting things, not a failure if you made their time comfortable and valuable, needed to work on emotional reactions, satisfaction and a sense of enjoyment, inspired.	100%	Sample selection and demographics unclear.
Donnelly, S. and Walker, S. (2021, New Zealand) Enabling first and second year Physicians to negotiate ethical challenges in end-of-life care: a qualitative study	Several participants described debriefing as particularly important for the Year 1 Physicians.	Difficulties with overdependence on the staff member, struggling / failure to articulate, frustration 'what was the point', apprehensive, distressing, balance, appreciation - lovely, being offered help-fantastic, cathartic processes / cup of tea given, I find it difficult saying I don't know what to do, emotive and challenging, grating, sickening, uncomfortable, compassion fatigue, not feeling valued, found it hard to juggle responsibilities, tricky, not being given the time of day, horrendous, so frustrating.	80%	Limited sample to junior Physicians, and sample of these could have been broader. Unclear about who completed interviews and whether they were known to interviewees. Unclear whether a debrief was included.
Economos, G., Bonneville-Levard, A., Djebari, I., Van Thuyne, K., Tricou, C., Perceau-Chambard, É. and Filbet, M. (2020, France) Palliative care from the perspective of cancer physicians: a qualitative semi structured interviews study	Four themes: symptom management as a trigger, psychosocial support, mediation provided by interventions, and the association with terminal care or death. Several barriers were identified, often due to the confusion between terminal care and palliative care. This was further highlighted by the avoidance of the words 'palliative care', which were associated with death.	Admissions of failure, frustration, and shame.	90%	Lacked exploration and follow-up questions related to feelings and emotions experienced.
El-Rouby, D., McNaughton, N. and Piquette, D. (2020 Canada) Painting a Rational Picture During Highly Emotional End-of-Life Discussions: a Qualitative Study of Internal Medicine Trainees and Faculty	Physicians depicted end-of-life discussions as a process directed at painting a realistic picture of a clinical situation. By focusing their efforts on reaching a shared understanding of a clinical situation with patients/families, physicians self-delineated the boundaries of their professional responsibilities regarding end-of-life care (i.e., help with understanding, not with accepting or making the "right" decisions). Information sharing took precedence over emotional support in most physicians' accounts of end-of-life discussions. However, the emotional impact of end-of-life discussions on families and physicians was readily recognised by participants.	Deep sense of responsibility, feeling of failure, failing as communicator, frustrating, don't want people to feel bad, intentionally avoiding thinking, uncomfortable, emotionally exhausting, tiring.	80%	No clear definition of end of life. Unclear whether any specific questions relating to feelings were asked explicitly.
Horlait, M., Chambaere, K., Pardon, K., Deliens, L. and Van Belle, S. (2016, Belgium) What are the barriers faced by medical oncologists in initiating discussion of palliative care? A qualitative study in Flanders, Belgium	Identified barriers which discourage oncologists from discussing palliative care: oncologist-related barriers, patient-related barriers, family-related barriers, barriers relating to the physician referring the patient to the medical oncologist, barriers relating to disease or treatment, institutional/organisational barriers, and societal/policy barriers.	Additionally difficult if they have known the patient, sadness and anger is hard to deal with, reluctance, admitting personal failure, inexperience as a barrier, unrealistic hope and expectation, difficulties in handling emotional reactions from patients, maybe simply personality differences?, fear that cultural or language issues cause miscommunication, not to cure equals failure, difficult to use certain words, feel solely responsible, avoid mentioning palliative care, demanding, stressful, exhausting.	70%	No clear or consistent definition of end of life, therefore participants could be considering different constructs. Broad research question, and so data collected may have been diluted. Unclear about the relationship between researcher and participants.

Authors (year, country, paper title)	Relevant findings	Emotions experienced by Physicians named in study	Quality assessment in %age of total	Limitations
Jox, R. J., Schaider, A., Marckmann, G. and Borasio, G. D. (2012, Germany) Medical futility at the end of life: the perspectives of intensive care and palliative care clinicians	The reasons for continuing futile LST are primarily emotional, such as guilt, grief, fear of legal consequences and concerns about the family's reaction. Other obstacles are organisational routines, insufficient legal and palliative knowledge and treatment requests by patients or families.	Concerns / fears about death, litigation, reaction by others. Also, helplessness, grief, guilt, applied mercy, and injured pride.	80%	Although emotions are named, this was not expanded on and explored by authors, and quotes sometimes edited, which affected the expression of emotional impact.
Lenherr, G., Meyer-Zehnder, B., Kressig, R. W. and Reiter-Theil, S. (2012, Switzerland) To speak, or not to speak -- do clinicians speak about dying and death with geriatric patients at the end of life?	Explored difficulties and barriers to discussing dying and death. The majority (21/31) of the interviewed physicians reported a considerable willingness to speak about dying and death with patients approaching the end-of-life. Obstacles to addressing this topic included external circumstances, such as lack of time and/or privacy (14/31); personal reasons, such as feeling confronted with one's own mortality (12/31); resistance or denial in their patients (12/31); and the cognitive state of the patients (7/31).	Fear of death, fear of failure, cultural taboo.	80%	The author included only a few basic quotes, none of which broadly explored the depth of emotion, but this was alluded to in discussion.
Nordenskjöld Syrous, A., Ågård, A., Kock Redfors, M., Naredi, S. and Block, L. (2020, Sweden) Swedish intensivists' experiences and attitudes regarding end-of-life decisions	Underlying factors that contribute to the variability in decision-making are lack of continuity among senior intensivists, lack of needed support during on-call hours and disagreements with physicians from other specialties. There is also an individual variability primarily depending on the intensivist's personality.	Fear of criticism.	100%	The paper did not name a broad range of feelings, but fear, particularly of criticism, was a recurring theme, and so was deemed appropriate for inclusion.
Owusuaa, C., van Beelen, I., van der Heide, A. and van der Rijt, C. C. D. (2021, Netherlands) Physicians' views on the usefulness and feasibility of identifying and disclosing patients' last phase of life: a focus group study	The medical specialist was considered mainly responsible for prognosticating and gradually disclosing the last phase. Participants' reluctance to such disclosure was related to uncertainty around prognostication, concerns about depriving patients of hope, affecting the physician-patient relationship, or a lack of time or availability of palliative care services. Identified that prediction is more difficult in patients with advanced organ failure compared with cancer. Considered 'an artificial border' that the Physician draws for themselves, and it has a different value for each patient.	General themes of apprehension, especially if you know the patient well, or if you feel you are destroying hope.	60%	Did not ask explicitly about emotions, and so although guesses can be made it is not made clear by the author. Included in review because emotions are named and within participant quotes.
Prod'homme, C., Jacquemin, D., Touzet, L., Aubry, R., Daneault, S. and Knoops, L. (2018, France) Barriers to end-of-life discussions among haematologists: A qualitative study	Themes included: as long as there are potential treatments haematologists fear that end-of-life discussions may undermine their relationship and the patient's trust. Due to their own representations, haematologists have great difficulty opening to their patients' end-of-life wishes. When prognosis is uncertain, negative outcome, that is, death, is not fully anticipated. Persistent hope silenced the threat of death.	Protecting self, protecting other, sense of failure is discussed, or death explored with patient or family or colleagues.	80%	Rich summaries but the quotes were brief and there was not clarity about how much time / depth was given to exploring emotions experienced.
St Ledger, U., Reid, J., Begley, A., Dodek, P., McAuley, D. F., Prior, L. and Blackwood, B. (2021, Northern Ireland) Moral distress in end-of-life decisions: A qualitative study of intensive care physicians	Two predominant themes: key moral distress triggers, and strategies and consequences. Junior residents reported most instances of moral distress, triggered by perceived futility, lack of continuity, protracted decisions, and failure to ensure 'good death'. Senior physicians' triggers included constraint of clinical autonomy. Moral distress was far-reaching, affecting personal life, working relationships and career choice.	Perceived futility, feelings of right and wrong, impact of senior colleagues' perceptions, and perceptions of family. Failure if not able to convince family. More stressful than troubling as age increases.	60%	This is a moral distress paper, and the authors define moral distress as an extreme emotional response, when constrained by personal limitations or organisational restrictions from doing what their conscience believes is the 'right thing'. They identify pre-existing research that suggests it causes enduring feelings of powerlessness, wrong-doing and breached integrity. This theoretical stance limited the questions around emotional experience and may also be a problem in that it could be restricting the meaning to external forces. The theory assumes that people want to do the right thing but factors around them stop them. What about internal factors like fear? Unclear in this regard.
Whitehead, P. R. (2012, Canada) The lived experience of physicians dealing with patient death	Themes indicate that physicians can experience very strong and lasting emotional reactions to some patient deaths, and that patient death can elicit intense experiences related to professional responsibility and competence. A key finding is the description of a complex process of managing the balance between personal and professional reactions in the face of patient death. The implication is that difficulties negotiating this balance may lead to unintended lapses in compassion and suboptimal outcomes in patient care.	Intense reactions, vivid recall, flood of sadness, emotion, grief, fear, just below surface, expectations vs reality, feelings of responsibility, balance, normalising, separating, exposed, needing to feel clean, comparison, created terror, setting aside emotional reactions, feeling in my stomach, hit home, deeply personal, makes you think about your own life and mortality, functional disconnect.	70%	Small sample size. Single hospital site perhaps limits generalisability. Given its connection to well know previous research could have influenced how participants responded.

Authors (year, country, paper title)	Relevant findings	Emotions experienced by Physicians named in study	Quality assessment in %age of total	Limitations
Wiersma, M., Ghinea, N., Kerridge, I. and Lipworth, W. (2019, Australia) 'Treat them into the grave': cancer physicians' attitudes towards the use of high-cost cancer medicines at the end of life	Physicians believe that the use of high-cost medicines at the end-of-life is driven by multiple factors – including individual, interpersonal, socio-cultural, and public policy influences.	Discomfort with death resulting in communication failure, difficult making predictions, assumptions about how other people fear death based on own experience, frightening, emotional, difficult feelings, difficulty distancing self, avoiding confronting other or self-mortality, fear, looking for easier less direct forms of communication, wanting to feels they've exhausted all other options, reluctance, hopeless, blaming people over system, feeling like playing a game, self-criticism, needing to 'get over it, scary, sense of finality.	60%	Considered the dilemmas in accepting death faced by people who treat cancer - identifies fears and obstruction to communication but lacks detail in how it collected information and the sample/population.
Willmott, L., White, B., Gallois, C., Parker, M., Graves, N., Winch, S., Callaway, L. K., Shepherd, N. and Close, E. (2016, Australia) Reasons Physicians provide futile treatment at the end of life: a qualitative study	Factors in why treatment is offered included firstly the characteristics of the Physician, their orientation towards curative treatment, discomfort or inexperience with death and dying, concerns about legal risk and poor communication skills. Secondly, the attributes of the patient and family, including their requests or perceived demands for further treatment, prognostic uncertainty, and lack of information about patient wishes. Thirdly, there were hospital factors including a high degree of specialisation, the availability of routine tests and interventions, and organisational barriers to diverting a patient from a curative to a palliative pathway.	Not giving up hope, emotional attachment, avoidance, discomfort, emotive Physicians, desire to satisfy others, worries about legal consequences, fear of making wrong decision.	90%	Paper drew out emotional themes even though it does not appear that feelings were planned to be elicited, based on the interview schedule (although information about the content of the interview schedule and direction of questioning is limited).
Zambrano, S. C., Chur-Hansen, A. and Crawford, G. B. (2012, Australia) On the emotional connection of medical specialists dealing with death and dying: a qualitative study of oncologists, surgeons, intensive care specialists and palliative medicine specialists	Key theme: Ambivalence about developing emotional connections with patients and families. Advantages of not engaging emotionally with patients were related to preserving objectivity in the decision-making process, while a perceived disadvantage was the loss of the opportunity to engage in meaningful relationships that could positively influence patients, families, and the medical specialist. Finding a balance in the face of ambivalence was a preferred approach and participants employed a variety of coping strategies.	'Getting emotionally involved', and 'seeking emotional distance'. These emotional coding themes were complemented by a third: 'finding a balance' in the emotional connection.	100%	Interviews edited by respondents, could introduce social bias. Interviewer was known to participants.

### **Methods Used by Included Studies to Capture Emotional Experience**

Emotional experience was captured in several different ways across the papers identified. Two papers identified the use of recording equipment and the capturing of specific words and changes in tone and speech to identify emotions experienced (Corradi, Duim, & Rodrigues, 2020; Donnelly & Walker, 2021). Others pointed to the orientation of the researchers, indicating they were explorative (Horlait et al., 2016), or involved psychologists at the interview stage (Crawford & Zambrano, 2015). Three papers referred to using prompts to encourage participants to reflect on feelings (Amati & Hannawa, 2014; Economos et al., 2020; Jox et al., 2012), and one asked about the meanings they attributed to memorable experiences (Prod'homme et al., 2018). The remaining papers were not clear about their method of drawing out emotional experiences from participants.

### **How 'End-of-Life' is Defined by Included Studies**

Only three of the papers explicitly defined what they meant by EOL. For two papers, it was defined using medical terminology related to specific medical specialties, for example when haematological malignancies reoccur (Prod'homme et al., 2018), and brain stem death (St Ledger et al., 2021). One paper simply defined it as expected death within one year (Owusuaa et al., 2021). Two papers asked participants for their perspective (Corradi et al., 2020; Crawford & Zambrano, 2015), or to define a set phrase like 'palliative care' (Economos et al., 2020), or 'futility' (Jox et al., 2012), or 'end-of-life' (Amati & Hannawa, 2014; El-Rouby, McNaughton, & Piquette, 2020). Two papers asked participants to recall memorable patient deaths and reflect on those experiences (El-Rouby et al., 2020; Prod'homme et al., 2018). One paper identified the difficulty that participants had in defining death (Corradi et al., 2020), adding that junior staff were more likely to go beyond

organic presentations to include elements like spirituality. The remaining papers did not give a clear definition, and so it was difficult to compare within and across these studies whether this affected how emotions were experienced. However, given that this review was looking at participants' emotional experiences, all definitions of EOL were considered acceptable, as even when unexplored by the author, the participant would be drawing from their own self-definition.

### **Themes**

Two broad themes were identified that summarised the challenges influencing a clinician's emotional experience of EOL communication and decision-making: the delicate shifts between: 1. desire versus ability; and 2. camouflage and hiding oneself versus revealing and the risk of exposure. Table 3 presents the themes identified and how often each review paper referenced each theme.

Table 3

*Themes and Their Identification in Each Paper, Including Number of Times a Paper References an Identified Theme\**

	Theme 1: Desire versus ability						Theme 2: Camouflage and hiding oneself or revealing and the risk of exposure			
	1.1: No clear direction or treatment – dealing with uncertainty	1.2: Knowing and accepting the limits of curative medicine without failure	1.3: Communication difficulties	1.4: Sense of expectation from self and others	1.5: Reluctance to make decisions – avoiding decision regret	1.6: General demands on time and energy competing	2.1: Relatability and connection	2.2: Revealing difficult news	2.3: Ultimate self-protection	2.4: Openness to explore emotional reaction
Amati, R. and Hannawa, A. F. (2014) (Amati & Hannawa, 2014a)	13	2	3	2	0	0	27	29	6	2
Corradi, M. L. G., Duim, E. and Rodrigues, C. I. S. (2020) (Corradi et al., 2020a)	6	7	1	0	0	0	4	0	1	0
Crawford, G. B. and Zambrano, S. C. (2015) (Crawford & Zambrano, 2015)	11	10	0	6	1	0	6	3	2	4
Donnelly, S. and Walker, S. (2021) (Donnelly & Walker, 2021)	6	7	4	4	2	4	16	1	0	0
Economos, G., Bonneville-Levard, A., Djebari, I., Van Thuyne, K., Tricou, C., Perceau-Chambard, É. And Filbet, M. (2020) (Economos et al., 2020)	3	6	0	1	0	0	0	0	0	0
El-Rouby, D., McNaughton, N. and Piquette, D. (2020) (El-Rouby et al., 2020)	0	2	5	7	0	1	7	4	3	0
Horlait, M., Chambaere, K., Pardon, K., Deliens, L. and Van Belle, S. (2016) (Horlait et al., 2016)	0	4	6	11	0	3	5	3	2	0
Jox, R. J., Schaider, A., Marckmann, G. and Borasio, G. D. (2012) (Jox et al., 2012)	1	1	0	0	0	0	0	0	0	1
Lenherr, G., Meyer-Zehnder, B., Kressig, R. W. and Reiter-Theil, S. (2012) (Lenherr, Meyer-Zehnder, Kressig et al., 2012a)	0	4	8	1	1	0	7	6	4	0
Nordenskjöld Syrous, A., Ågård, A., Kock Redfors, M., Naredi, S. and Block, L. (2020) (Nordenskjöld, Ågård, Kock Redfors et al., 2020)	9	7	0	7	2	0	0	2	0	1
Owusuua, C., van Beelen, I., van der Heide, A. and van der Rijt, C. C. D. (2021) (Owusuua et al., 2021)	1	1	1	4	0	0	3	2	0	0
Prod'homme, C., Jacquemin, D., Touzet, L., Aubry, R., Daneault, S. and Knoops, L. (2018) (Prod'homme et al., 2018)	1	0	7	7	0	0	3	4	1	0
St Ledger, U., Reid, J., Begley, A., Dodek, P., McAuley, D. F., Prior, L. and Blackwood, B. (2021) (St Ledger et al., 2021)	4	12	4	9	2	0	4	1	7	1
Whitehead, P. R. (2012) (Whitehead, 2012)	0	2	0	16	1	0	23	0	9	0
Wiersma, M., Ghinea, N., Kerridge, I. and Lipworth, W. (2019) (Wiersma, Ghinea, Kerridge et al., 2019)	1	5	2	2	0	0	1	4	3	0
Willmott, L., White, B., Gallois, C., Parker, M., Graves, N., Winch, S., Callaway, L. K., Shepherd, N. and Close, E. (2016) (Willmott, White, Cartwright et al., 2016)	0	4	0	8	1	0	7	2	1	1
Zambrano, S. C., Chur-Hansen, A. and Crawford, G. B. (2012) (Zambrano, Chur-Hansen, & Crawford, 2012b)	2	5	0	4	0	2	30	0	13	4

\*Note. Green colour indicates a paper has at least one reference to that theme. Red indicates that the corresponding theme was not referenced in that paper.



**Theme 1: Desire Versus Ability**

This theme relates to the influence of perceived ability, skill, and level of responsibility in making the best choices for patients at the EOL, and how ability is often mediated by whether there is also a desire to engage in the death process. Several limiting factors were identified that influenced both a person's perceived ability to respond to a patient's needs, as well as their desire to respond. The main subthemes were 1.1: Dealing with uncertainty when there is no clear direction or treatment to offer; 1.2: Knowing and accepting the limits of curative medicine without failure; 1.3: A sense of expectation from self and others; 1.4: Communication difficulties; 1.5: Avoiding decision regret; and 1.6: Competing demands (Table 4).

Table 4

## Theme 1 'Desire versus Ability' Subthemes and Illustrating Quotes

Sub theme	Summary definition	Illustrative quotes (with paper and page number)
1.1: No clear direction or treatment – dealing with uncertainty	Wanting to offer support, but uncertainty leads to fear, reluctance and discomfort.	<i>"If there is only the slightest uncertainty, it may feel hard to make a decision and therefore one chooses to defer it"</i> (Nordenskjöld, Ågård, Kock et al., 2020) p.658  <i>"We, as physicians, try to bring predictability to secure ourselves"</i> (Amati, & Hannawa, 2014) p.966
1.2: Knowing and accepting the limits of curative medicine without failure	Avoidance of wanting to feel defeated by death leads to ineffective continuation of treatment and denial of illness. Support from others helps to refocus goals from cure to quality of life.	<i>"Often there is a surgeon involved who... is still up to a cure, and for whom it is hard to accept that he cannot go any further at that point. He has to be heard, and this can take a while."</i> (Jox, Schaidler, Marckmann et al., 2012) p. 542  <i>"[I was] surprised that the palliative care team was prepared to have discussions about their own reactions to particular cases and to provide support to each other... it's helped me to develop a passion for quality of life and patient care."</i> (Crawford & Zambrano, 2015) p.341
1.3: Communication difficulties	Wanting to communicate in a way that makes others understand and agree. Disappointment, guilt, shame, and failure if this is not achieved, or dismissing the patient and their opinions as a possible method of self-protection from these feelings.	<i>"I think the only time I feel I have failed is when I feel the family did not understand the facts."</i> (El-Rouby, McNaughton, & Piquette, 2020) p.1170  <i>"There are people who just don't want to hear about it, and they fight until the end [...] you cannot talk openly."</i> (Lenherr, Meyer-Zehnder, Kressig, et al., 2012) p.4
1.4: Sense of expectation from self and others	Self-criticism and perceived criticism results in frustration and shame. Physicians felt unsupported and exposed, whilst also feeling like they should not need support, resulting in feeling like a failure.	<i>"During the medical education we are taught: 'we are Physicians, we have to cure!'"</i> (Horlait, Chambaere, Pardon et al., 2016) p.3878  <i>"Concerned that discussion of the last phase of life may trigger fear in patients or let patients think that the physician is giving up on them"</i> (Owusuaa, van Beelen, van der Heide et al., 2021) p.4
1.5: Reluctance to make decisions – avoiding decision regret	Preference to feel comfortable and avoid feeling overwhelmed by the reality of death and patient reaction.	<i>"Preventing "decision regret" depended on having courage of convictions and giving "every chance of survival""</i> (St Ledger, Reid, Begley et al., 2021) p.187  <i>"The terror of... how deeply responsible I felt to be competent in that moment, and how the chance of not being able to do something, or not doing it right, is so overwhelming."</i> (Whitehead, 2012) p.273
1.6: General demands on time and energy competing	Juggling work demands means less time to experience and process emotion and may make the experience more intense and overwhelming.	<i>"I was a bit apprehensive to go and have that discussion to start with as well, because I knew that while I was in there having this quite personal and distressing discussion that I didn't want to rush, there was also all of these other jobs piling up."</i> (Donnelly & Walker, 2021) p.3  <i>"I had to come back and do all the paperwork and do the confirmation of life extinct, with that emotion still pounding through. I found that quite hard".</i> (Donnelly & Walker, 2021) p.3

**Dealing with Uncertainty When There is No Clear Direction or Treatment to Offer**

Physicians wanted to offer treatment, support, and reassurance to a patient but were unable to do so, and this left them with an uncomfortable feeling of uncertainty, inadequacy, guilt, and pressure. This was described as being linked to medical training and

its focus on 'curing' being the key role of physicians, and the level of predictability and security this brings. Language like 'impotence' and 'inadequate' and 'powerless' (Amati, & Hannawa, 2014) were used by some physicians to describe how it feels to know that death is not within their ultimate control. Describing discomfort, words like 'strangeness' and phrases like '[it] stirs this sort of bad feelings in me' (Corradi, Duim, & Rodrigues, 2020) illustrated how foreign this feeling, and sense of powerlessness, was to many and how medicine may encourage an identity of precision and certainty. There was a link between feeling like EOL care was a passive role, and that an active and heroic stance was more authentically a physician's place, and EOL work should be 'passed on' (Donnelly & Walker, 2021) to someone else to maintain this active stance. Those who had received training in palliative care were still uncomfortable about this uncertainty but felt less guilt about the limits imposed by EOL situations.

### ***Knowing and Accepting the Limits of Curative Medicine Without a Sense of Failure***

Knowing and acceptance were identified as influencing the decisions physicians made about treatment. Within this, there was evidence that power played a role in acceptance – the wrestle of power between illness and physician, the power balance between medical professionals in a team, and the power dynamics between patient and physician. Authors captured shifts in body language and changes in speech as participants were asked about this wrestle, with one study adding 'within seconds, the interviewees seemed to move outside of their comfort zone' (Corradi, Duim, & Rodrigues, 2020). Those who felt defeated by EOL illnesses struggled to make decisions and felt impotent. However, there was a fine balance between self-confidence and belief in medicine and this can result in a battle between the illness, medicine, and practitioner ego. Participants reported

'surprise that [others were] prepared to have discussions about their own reactions to this particular case' noting how vulnerable that might leave them feeling (Crawford & Zambrano, 2015). Sometimes, a close relationship with a patient resulted in prolonging ineffective treatment, as a gesture of rapport. Positive shifts in power and acceptance were related to seeing consultants or other teams offering support to junior staff and sharing openly the effects EOL treatment can have on them, too, and knowing when to hand over to palliative care teams without a sense of failure. Frustration was linked to seeing consultants express the sense of 'all-powerfulness' and a resistance to death.

### ***Communication Difficulties***

Many physicians reported finding reward in being able to explain a difficult situation in a way that can be understood by a patient and relatives, but when this is not achieved it can feel challenging: 'I think one of the things we struggle with is really painting a picture of what [the future] might look like' (El-Rouby, McNaughton, & Piquette, 2020). When there was misunderstanding, a negative reaction, or lack of agreement with the physician's ideal treatment plan, it resulted in reactions by physicians which included assuming patients and relatives did not want to know about their condition, feeling that they were dismissing the patient and their opinions, or guilt, shame, and a sense of failure about not being able to communicate in a way the patient could understand. Physicians also raised the challenges related to learning disabilities or cognitive impairments, and what this means for decision-making, adding to personal pressure. Some felt like communication around death only ever brought pain and suffering for all parties: 'All we have is bad news' and that 'we never get coaching from nobody' (Horlait et al., 2016).

### ***A Sense of Expectation from Self and Others***

Perceived criticism impacted upon how events were emotionally processed. This was a combination of self-criticism, and perceived criticism from others, both patients and colleagues, which resulted in frustration and shame. Failure was experienced when physicians set themselves unrealistic expectations, or when they felt unrealistic expectations were put on them by others. They felt that demands were being placed on them by all aspects of the medical structure, including patients, relatives, other team members, management, hospital structures, legal and ethical frameworks, and medical training. Criticism from colleagues was described as being implicit rather than explicit, due to feeling unsupported and exposed. Knowing what patients and families wanted and being unable to offer it left physicians feeling unhelpful at least, and often dispirited. The cumulative effect has been described as a 'terror ...of feeling deeply responsible' (Whitehead, 2012). Level of experience was also a notable factor – junior physicians reported a dilemma between feeling unsupported but also feeling like they should not need support. Even those who voiced concerns about not getting enough support from senior members of their team still described a sense of personal inadequacy, and a feeling of failure. There were comments from junior physicians about how they are surprised they do not see more of their senior colleagues experiencing stress and burnout. Many reported dealing with this sense of failure by cutting off from other colleagues, not asking people how they are coping, resulting in a vicious cycle of not supporting colleagues, especially newer members of the team. However, those who could see that death did not equal failure felt more positive and hopeful.

### ***Avoiding Decision Regret***

A desire to feel comfortable and emotionally stable was shown to sometimes eclipse delivering difficult news or making decisions at the right time. Differences in decisions or how news was relayed to patients were sometimes described as being due to differences in perceptions about what was in the patient's best interest when they may instead be the result of personality-type and avoidance behaviours. One participant said that their observation was that physicians sat between two camps: '[those with a] reluctance to make a decision right up to the very last or [those] who makes decisions prematurely' (Nordenskjöld et al., 2020). Physicians described this as avoiding 'decision regret', and the overwhelming feelings that come with it. On occasion, physicians defended this as helping to maintain hope for the patient.

### ***Competing Demands***

Physicians reported finding it difficult to make decisions and have difficult conversations at EOL whilst also having to juggle other work demands, including talking to people about EOL, and completing the paperwork related to another patient's death, making the experience of emotion more intense and overwhelming. Distancing from emotions was a tool used to 'help you think properly' about other demands (Zambrano, Chur-Hansen & Crawford, 2012). Having the support of other team members, who can make the physician 'a cup of tea' and give them 'a quiet space', was reported as helping with managing these feelings of distress. Not having emotional support from senior colleagues was related to experiences of burnout and exhaustion and 'finding it so frustrating' (Donnelly & Walker, 2021).

## Theme 2: Camouflage and Hiding Oneself Versus Revealing and the Risk of Exposure

This theme relates to the experience of physicians who choose not to have meaningful relationships with patients, and the impact this can have on the physician at the EOL. To hide oneself and one's emotions may be a defence against the risk of being hurt or having one's own personal sense of mortality activated but may result in a disconnect between patient and physician. The main subthemes were: 2.1 Relatability and connection; 2.2 Revealing difficult news; 2.3 Ultimate self-protection; and 2.4 Openness to explore emotions (Table 5).

**Table 5**

### *Theme 2 'Hide versus Reveal' Subthemes and Illustrating Quotes*

Sub theme	Summary definition	Illustrative quotes (with paper and page number)
2.1 Relatability and connection	Closeness to patients may lead to an increased sense of loss, sadness and grief, and a sense of accountability. Those who close-down emotional experiences say they are less affected and can think more clearly.	<i>"Over time, I think we always have a lot of contact with relatives, patients...sometimes it's difficult, right? You develop a bond, you come to know the person...when he/she dies you feel..., in my case...I feel pain..."</i> . (Corradi, Duim, & Rodrigues, 2020) p.3  <i>"If one day I feel more fragile I prefer to tell them what is going on and then leave, because I know that if I get too involved then I might have a crisis myself."</i> (Amati, & Hannawa, 2014) p.966
2.2: Revealing difficult news	Discussing death is emotionally triggering and activates other feelings of personal loss. Therefore, how news is delivered by a physician may be impacted by the avoidance of emotional triggers.	<i>"[Offering] futile treatment... was attributed to avoidance and discomfort with a conversation about dying."</i> (Willmott, White, Gallois et al., 2016) p.498  <i>"In their personal time when sleeping or being at home or with friends, these cases could come to mind, particularly if there were some unresolved issues or emotions."</i> (Zambrano, Chur-Hansen & Crawford, 2012) p.237
2.3: Ultimate Self protection	Avoiding emotional triggers is often described as essential to getting through heavy workloads. But this avoidance often grew from avoiding words, to conversations, to patients and then to wards and parts of the hospital. It resulted in poor relationships and fear or coldness.	<i>"When I'm worried about something, then I'm more blocked and closed."</i> (Amati & Hannawa, 2014) p.966  <i>"Depending on the patient ... there are impressive repressing mechanisms."</i> (Lenherr, Meyer-Zehnder, Kressig et al., 2012) p. 4
2.4: Openness to explore emotional reaction	Finding a balance between openness and self-protection helps with long-term processing of events. Seeing this modelled was regarded as the most effective method of learning.	<i>"Not being able to talk openly, maybe even just to cry together, it's something that takes away many opportunities to heal the situation and elaborate on what's going on."</i> (Amati & Hannawa, 2014) p.969  <i>"Being aware of their level of emotional engagement meant that a conscious assessment of their emotional response [led to recognition] of the extent of their involvement."</i> (Zambrano, Chur-Hansen & Crawford, 2012) p.272

### ***Relatability and Connection***

Allowing oneself to feel a connection to a patient was found to involve a degree of opening oneself up to being affected, both positively and negatively, by the experience of the patient. Those close to patients reported offering additional treatment options to avoid upsetting a patient or help them manage the difficult experience of losing a friend, including coping with sadness, grief, and loss. To open up also brings with it exposure, and the increased sense of accountability, both in terms of exposure to the patient, and to senior colleagues or managers. Further, relatability, for example a patient sharing features of a child or parent, often triggers personal distress, with one physician commenting 'I know that if I get too involved then I might have a crisis myself' (Amati, & Hannawa, 2014). When connection is experienced, a sense of responsibility also increases, whereas those who close down emotional experiences feel like they can think more clearly and are less affected by personal distress. A balance between these two is 'difficult... but possible' (Crawford & Zambrano, 2015).

### ***Revealing Difficult News***

Physicians reported finding the sharing of difficult news emotionally triggering and indicated that it activated other personal feelings of loss. Unlike subtheme 1.3, this subtheme is not about patient misunderstanding or communication difficulties outside the physician's control, but, instead, the way news is delivered differently depending on how much emotional exposure the physician is willing to experience. Several different factors were described as limiting a physician's willingness to openly discuss EOL communication, and these included discomfort with personal mortality, reluctance to experience other people's distress, and reluctance to feel their own distress – described by physicians as



'hiding behind the numbers' (Amati, & Hannawa, 2014) and 'adopting a false positive attitude' (Prod'homme et al., 2018). However, being prepared, seeing it done well and being praised by patients or senior colleagues resulted in it feeling less emotionally daunting and triggering.

### ***Ultimate Self-Protection***

Physicians used several techniques described in one paper as 'impressive repressing mechanisms' (Lenherr et al., 2012) to avoid personal distress and a sense of being overwhelmed, both in the moment, but also later within their personal time. This included avoiding certain patients, departments or specialisms, distraction with other work tasks, denial about patient needs or the need for relationships within decision-making, going into situations unprepared and unable to answer questions 'almost like you turn off part of your brain' (Whitehead, 2012), not knowing referral pathways so that EOL is not discussed, poor relationships with palliative care teams and a resentment of their methods as facilitating patients to 'give up hope' (Horlait et al., 2016), and over emphasising scientific language so it is difficult for others to fully comprehend and respond to information.

### ***Openness to Explore Emotions***

Some physicians reported finding a balance between openness and self-protection and experienced a greater sense of connection to themselves and the world around them when they tried to understand the emotions they had experienced with patients and at work – creating 'many opportunities to heal' (Amati & Hannawa, 2014). However, being more emotionally aware was not always seen as positive, and those who may be more emotionally aware and prepared to experience death, were also described as being more

emotionally affected by it in the moment, and this was seen as a problem by some – ‘[I see those who] work more closely with the patients ... experience moral distress’ (Nordenskjöldn et al., 2020).

## Discussion

This review has synthesised a relatively unexplored area of research: the emotional experience of physicians in acute settings responding to patients who move to EOL treatment. The review identifies that a range of emotions are experienced when working in EOL care. It has found support for a relationship between events in EOL care, subsequent emotions experienced, and resulting changes in thinking and behaviour in the delivery of care, as was suggested by Balch & Copeland (2007) and Ofri (2013). It also adds support to the theory of motivation suggesting that types of emotion may have different impacts on the motivation of behaviour, where perceived negative experiences may prime avoidance, and positively perceived experiences may prime approach-related behaviours (Kozlik, Neumann, & Lozo, 2015). Two dominant themes were evident across nearly all the papers reviewed: firstly, the emotional impact when faced with a tension between a physician's desire to respond to patient needs and their ability to do so; and, secondly, the conflict between camouflage and hiding oneself and one's emotions, and whether to reveal aspects of oneself and risk exposure and potential emotional fallout.

A physician's *perceived* ability to respond to a patient's needs, and the *desire* to respond to those needs, both seemed to influence how effective EOL care is emotionally experienced. Perception of personal self-efficacy was linked to one's sense of feeling able and prepared to handle the emotion and connection that EOL care brings. This is consistent with other studies that have found that self-efficacy links directly with the achievement of palliative core competencies in medicine (Moyer et al., 2020), and has been found to play a more meaningful role in the application of effective EOL care than simply an acquisition of knowledge, by up to 32% (Gilissen et al., 2020). Self-efficacy is a core construct of social

learning theory, which suggests that learning and a sense of confidence and competence occurs most profoundly in social contexts and during social interactions (Bandura & Walters, 1977). People with low levels of self-efficacy have been found to avoid situations that have led to failure in the past, whereas high self-efficacy provides motivation towards effort expenditure, independence, and persistence in the face of discomfort and distress (Bandura, 1993).

How physicians feel they are perceived by others was also shown to affect decision-making and behaviour. Whilst this can be a protective system, controlling for un-bounded displays of power and heroism, avoiding appraisal from others due to the risk of it being negative or critical may be an unhelpful system that hampers effective development by avoiding this threat, and in turn undermines self-efficacy. The themes in this review point repeatedly to the role that relationships and connection, with both patient and fellow medical professionals, play in the decisions a physician makes. The value and meaning attributed to relationship in healthy and effective medical decision-making has been well reported (Chipidza, Wallwork & Stern, 2015; Dang et al., 2017; Gordon & Beresin, 2015). In our review, empathy was found to be directly linked with allowing emotion to be experienced, and for relationships to form with patients and supervisors. The reluctance to feel vulnerable, whether this was the vulnerability related to not being able to give a clear response, of having to ask a senior member of staff for help or demonstrating communication skills to a junior member of staff, or of feeling a connection to a patient, contributed to distancing and defensive practices.

In this review, we have identified that perceived self-efficacy is closely linked with having supportive relationships with senior clinicians who can demonstrate good practice, including sharing their own emotional responses to EOL care. This was a theme that emerged from participants comments but was not reflected in the demographics (age or experience) recorded, or considered as a topic within interview schedules, within the papers reviewed. Only one paper reported asking participants about their previous EOL training and an understanding of their competence (Economos et al., 2020), which may be an indication of how training and competence is not fully appreciated when evaluating EOL experiences. Education level and time spent working with dying patients has been shown to further enhance palliative care knowledge and self-efficacy (Kim & Gray, 2021). Self-efficacy and EOL care has been shown to improve following observation of senior colleagues in a number of nonspecialised settings, indicating that learning through observation may be transferable (Gryscek et al., 2020). These findings may also support motivational theory's suggestion that emotional experience can have a cyclical effect in systems, with positive emotional experiences improving motivation to support others to achieve goals. It also implies that the reverse may also be true, with negative emotional experience impairing not only personal goals but also the desire to motivate and support others (Caraway et al., 2003). Given the difficulties in teaching EOL competencies to medical students (Schroder et al., 2009), a shift from positivist to social constructivist theoretical stance in medical education may encourage engagement with more complex social and emotional challenges (Mann, Dornan & Teunissen, 2011). Social learning theories and the methods that have developed from these, such as Kolb's Learning Cycle, may also help in acquiring and applying knowledge in medical teams (Taylor & Hamdy, 2013).

Of all emotions identified in the review, the emotion of fear was frequently connected to the behaviour of avoidance. This included fearing a loss of credibility, fear of criticism, fear of jeopardising patient compliance, fear of affecting treatment efficacy or making the wrong decision, triggering fear in patients and other patient reactions including anger, and fear that patients will not understand the situation, with some preoccupied with the impact this would have on them rather than the patient. Fear was also the word used to refer to a reminder of personal mortality, including an assumption that if a physician has a fear of death, so will their patient. Failure and fear were also shown to be inter-related, which is consistent with social-constructivist and social learning theories most commonly described using Bandura's self-efficacy theory (Bandura, 1993; Locke & Latham, 2002), where the prediction of being involved in undesirable social behaviour, as perceived by self and others, can increase negative emotions about the self (Locke, Motowidlo, & Bobko, 1986; Ryan, 2013). It is also consistent with early fear of failure literature, where failure is rooted in self and other perception and evaluation (Conroy & Elliot, 2004). Failing and failure most often described a failure 'to cure', that this was a sign of 'professional failure', and that patients could attribute a sense of failure to a physician as much as a physician could feel their own sense of failure. Other studies have observed this process in physicians, described by Walsh, Hagan, & Gamsu (2000) as 'hero to zero', when a wished-for miracle fails to materialise, and the sense of failure is felt.

### **Strengths and Limitations**

Notable strengths of this study include an extensive search strategy, and the use of two quality checklists to evaluate the papers. This review also benefits from the process of

mapping themes across all papers, to give the reader a sense of the strength of the themes comparatively across all the papers.

There were, however, several limitations to this study. Firstly, whilst the US model of clinical care is notably different to those in other parts of the world, there are implications of excluding studies from such a developed healthcare environment. Further research could explore similarities or differences identified between these healthcare systems.

Secondly, this study focused on the acute pathway of EOL care, which is only one of many pathways of EOL care. In acute settings, we identified that duty of care and decision-making sit with the physician, whereas in other pathways, the responsibility for EOL communication and decision-making may sit with other members of the clinical team. A wider study, possibly including other pathways of care and medical professionals, may generate different data.

Thirdly, very few of the studies scored highly in terms of quality, and many papers neglected to report known bias, including whether the interviewer was known to the participant. Only one paper reported the diversity of participants (Whitehead, 2012), and within this study, all participants were Caucasian. This may reflect a wider inattention within this field to consider the role culture, heritage, race, and power play in how emotions are experienced in EOL care. Many papers did not define EOL objectively, and this may have affected the validity of comparing across the studies with some of the data. However, it is unlikely to have affected the participants' self-defined experiences of EOL, which was the primary focus of the review. Overall, the papers represented a heterogeneous body of low-level evidence,

with a wide range of differences in participants, design detail i.e. interview schedule, biases, and conclusions. As this field of research develops, more homogeneity, especially in design and participants, will make comparison and review potentially more reflective of medical practice within specific populations and settings.

Fourthly, very few papers were explicitly designed to explore clinician emotions. Papers were included in this review because they identified emotions experienced by physicians within their data. Given that emotion was not a primary focus of the papers, emotions may have been intentionally or unintentionally excluded by researchers collecting the data, and by the authors reviewing the data, biasing the results. Further, only a limited number of studies explicitly contained questions about how physicians felt in relation to events, and therefore there may be more to explore in terms of physicians' emotional experiences. For this reason, this review has attempted to draw themes from all data reported in the papers selected. This includes commentary from authors, and references to body language and subtext named in papers. This therefore could be considered a strength of the analysis in this review, but also could be considered a weakness in that this review does not wholly draw from what participants have explicitly said, as reported within reviewed studies.

Finally, given that this research has found that one's perception of self and others is important for subsequent motivation and behaviour, one must consider how these factors also affect researchers, and how research is developed, understood, interpreted, and presented. The quality assessment showed that very few authors presented a reflexive statement, considering how their own experiences and social constructs may impact the development of their study. Qualitative research needs to continue to promote honest



researcher reflexive statements, especially when the research is asking participants to reflect on the experiences that have affected them.

### **Clinical Implications**

Whilst medical education has focused on behaviours and techniques of EOL communication and care, this study suggests that knowledge acquisition alone is not enough to produce effective physicians. To build self-efficacy, one must consider the role that cognitive and emotional components play, and how modelling from senior colleagues can either negatively or positively impact this emotional response. On a macro level, this review has highlighted the role of psychological understanding in the development of effective clinicians who are aware of the cognitive processes that may be limiting or enhancing their practice, and this psychological understanding of 'the self' and motivational theory should be incorporated into policy and medical training, and the wider healthcare system. On a meso level, integration is still needed between general medical teams and other care teams and specialties, especially palliative care teams. Organisations should promote the view that training about the role of palliative care reduces a sense of personal and professional guilt in teams when faced with uncertainty about EOL decisions. On a micro level, individuals should recognise the role of reflection, both personal and with colleagues, and healthcare organisations should create space and opportunity to make reflection possible. Reflection was indicated as being able to help normalise emotional experience and reduce a person's sense of failure when working at the EOL. Empathy was found to be directly linked with allowing emotion to be experienced. All these psychological processes present an opportunity for clinical supervision to be developed further in

medicine. Given that Clinical Psychology has clinical supervision as one of its core tenets, it is in a unique position to support the development of this structure in medical settings.

### **Future Research**

Only a limited number of studies exist that explicitly asked physicians about their emotional experience of working with EOL patients. Further, papers that had a mixed discipline research team, containing clinicians experienced in EOL care, as well as psychologists, asked a wider range of questions and, as a result, offered more contextual insights. Psychologists are likely to be able to offer unique contributions to medical research, and future research studies should consider multi-disciplinary research teams in the development of interview schedules and the interview process and aim to proactively identify the emotional impact of medical practice. It should also explicitly look at some of the key emotions identified in this review, namely fear and perceived failure.

### **Conclusions**

This review suggests that physicians experience a range of emotions when working with EOL patients, with more negative emotions being associated with poor self-efficacy, and a lack of senior figures to observe and with whom to reflect. Fear, namely fear of how they are being perceived by others, is indicated as a driving factor for avoidance behaviours.

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## Chapter 3: Empirical Study

### The Effect of Fear of Failure on Confidence in, and Comfortableness with, the Delivery of End-of-Life Care

As prepared for the Journal of Cognition and Emotion, in the required reference style of APA. Author guidelines for this journal can be found here:

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#### Authors

John Latham<sup>1\*</sup>, Sarah Butchard<sup>2</sup>, and Stephen Mason<sup>3</sup>

<sup>1,2</sup>Department of Clinical Psychology, Institute of Primary Care & Mental Health, University of Liverpool, Liverpool, United Kingdom

<sup>3</sup>Post-Graduate Lead for Palliative Care, School of Medicine, Institute of Life Course & Medical Sciences, Faculty of Health & Life Sciences, University of Liverpool, Liverpool, United Kingdom

#### Key Words

Physician, doctor, nurse, end of life, palliative, fear of failure, self-efficacy, psychology, medical education

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## **Abstract**

### **Objective**

To investigate whether fear of failure (FOF) influences a clinician's perception of their confidence and comfortableness with the delivery of end of life (EOL) care, controlling for gender, role, years of experience, and number of EOL conversations.

### **Methods**

Cross-sectional questionnaire study, using the Performance Failure Appraisal Inventory, the Self-Efficacy in Palliative Care scale, the Thanatophobia Scale, and analysed using a two-step multiple regression. Recruitment was across two large NHS hospital trusts in the UK, and national UK professional networks.

### **Results**

Participants included 104 doctors and 101 specialist nurses across 20 hospital specialties. The study validated the use of the PFAI and its subscales within a novel population. No. of EOL conversations, gender, and role impacted confidence and comfortableness with EOL care. Fearing loss of interest negatively impacted a clinician's confidence in communicating with patients. Fear of devaluing one's self-estimate negatively impacted confidence in decision-making, working with others, and self-efficacy.

### **Conclusion**

Three aspects of FOF negatively impacted both doctors' and nurses' delivery of EOL care.

**Clinical Implications**

Further study should explore how FOF develops, sustaining factors, and other areas of clinical practice that FOF impacts, drawing also from FOF research outside the field of medicine. Techniques developed to manage FOF in other populations can now be investigated with a medical population.

## Introduction

Care at the end-of-life (EOL) is considered one of the most difficult aspects of medical practice (Brown, 2019). Guidelines provide clinicians with recommendations for how to offer the most effective EOL care (Crawford et al., 2021; NICE, 2019) and training in EOL care is now integrated into all undergraduate training for doctors (General Medical Council, 2020) and nurses (Nursing & Midwifery Council, 2021). These guidelines and stipulations within the curricula from professional bodies reinforce that good care at the EOL is the responsibility of all HCPs, and that prognostic disclosure should aim to be comprehensive, timely, and included regularly in conversations with the patient to ensure high quality care (Al-Samkari, 2020).

Adhering to these recommendations has been shown to benefit both patients' and clinical staff's experiences of EOL processes and treatment. It helps to establish clear expectations, emphasises the importance of planning and preparing oneself and family, reducing travel and treatment costs for patients and medical professionals / services, and enables a more effective grief and bereavement process for family and medical teams alike (Mack et al., 2010; Morasso et al., 2015; Wright et al., 2008). In a study of cancer patients, realistic discussions of prognosis, paired with early palliative care, decreased the overuse of unnecessary interventions and, perhaps counterintuitively, prolonged patient survival (Nipp, El-Jawahri & Temel, 2019; Temel et al., 2017).

### Barriers to Effective EOL Care

Despite the effectiveness of these recommendations, there appear to be several barriers to implementing them in everyday practice (Draper et al., 2019; Temel et al., 2020). Contrary to evidence-based guidance, medical teams may present patients with prognostic uncertainty under the guise of sparing them distress. For example, a study of 1193 patients with incurable metastatic lung or colorectal cancer demonstrated that 74% of patients believed that chemotherapy could cure their cancer, with a clear indication that obscure patient messaging led to these unhelpful beliefs, and a more traumatic experience at the EOL (Weeks et al., 2012).

Several contextual factors have been presented to explain the barriers to effective EOL conversations, including the impact of cultural taboo (Lenherr et al., 2012), challenges with patient comprehension (Prod'homme et al., 2018) or competing demands on time and energy (Donnelly & Walker, 2021). However, it appears that psychological factors may be more often central to this issue. These factors include healthcare staff heroism (Whitehead, 2012), a desire for paternal control (Litvina, Novkunskaya & Temkina, 2020; Zambrano et al., 2012), apathy as a form of abstention (Corradi, Duim, & Rodrigues, 2020), fear of uncertainty (Amati & Hannawa, 2014), decision regret (Horlait et al., 2016), a sense of expectation of oneself and others and the resulting fear of failure (St Ledger et al., 2021), death anxiety and the reminders of the mortality of self, friends or family (Donnelly & Walker, 2021), and protecting oneself from the experience of grief (Zambrano et al., 2012). All the above have all been linked with avoidance of or difficulty with effective EOL communication in qualitative interviews with doctors in acute settings.

Of the identified psychological factors, to our knowledge, only one psychological construct has been empirically investigated in EOL settings. Death anxiety, a reminder of one's own mortality and vulnerability to death, and the impact this may have on sharing in someone else's EOL experience (French, Greenauer, & Mello, 2017), has been shown to impact a clinician's empathy, style of communication, the level of detail within communication, and clinical decision-making (Black, 2007; Neumann et al., 2011; Rodenbach et al., 2016).

However, the most recently published systematic review investigating this construct has been unable to find collective evidence to suggest that death anxiety is substantially responsible for limiting the application of taught skills and the implementation of guidance and triggering avoidance of EOL conversations and care (Draper et al., 2019), indicating other factors may play a role in this phenomenon.

Psychological factors remain the most likely cause of ineffective or avoided EOL care. Stress, threat, and anxiety have been shown to reduce capacity for frontal cortex activity, the means for processing emotions and building relationships, allowing for practical tasks to take priority, and reducing the ability to hold more challenging, complex, and emotionally laden conversations (El-Rouby et al., 2020; Prod'homme et al., 2018). Fear has been found to limit one's ability to intake information and reduce learning and revision capacity, as well as increase sensitivity to the perceived threat (Lang, Davis, & Öhman, 2000). It has been found to negatively impact an individual's ability to empathise, due to a focus on their own survival and self-protection, with a difficulty in dividing their attention to include others (Hojat et al., 2004). Bearing witness to death is well known to have several psychological impacts on functioning and wellbeing. It can evoke feelings of fear, anxiety, sadness, grief, fatigue, rumination on risk, vulnerability, injustice, helplessness, and powerlessness (Figley,

Bride, & Mazza, 1997; Liu, Forbat, & Anderson, 2019; Routledge et al., 2010), with many of these found affecting medical professionals despite regular exposure (Bouri et al., 2017).

Within the medical population, death is considered by some as professional failure, a loss of credibility, and the anticipation of the death of a patient can be seen as a prediction of the event, often resulting in a loss of motivation (Prod'homme et al., 2018). A relationship has been demonstrated between physicians feeling powerless in the face of death and reported avoidance behaviours (Bouri et al., 2017; De Vries et al., 2018). Kent, Anderson and Owens (2012) found that negative factors, including perceptions of inadequacy, unpreparedness, and self-criticism, limited the ability to learn from experiences and feel a sense of reward following intervention. However, clinical settings that are more familiar and prepared for death often see positive effects in terms of clinicians' approaches to care and their attitudes towards patients. This then has a bidirectional impact on the wellbeing of those receiving care, and their own anxiety response to death (McKenzie et al., 2017).

Outside of clinical settings, namely in education, business, and sports performance, the impact of fear, namely fear of failure (FOF), as a barrier to performance has been widely researched (Correia & Rosado, 2018; Jackson, 2017; Ng & Jenkins, 2018). However, empirical research is yet to explicitly investigate the role FOF plays in the delivery of EOL care in acute medical settings. What is known is that clinical staff who perceive a patient's death as a personal defeat have been found to hold on to grief, avoid further experiences of death, and categorise death as 'bad' (Costello, 2006; White, 1988). Further, medical teams where treatment is not primarily orientated towards EOL prognosis and care, or where the focus of the team is to reduce the likelihood of death, feel the impact of a patient's death

more acutely and personally (Prod'homme et al., 2018). Mann, Dornan & Teunissen (2011) suggest that it may be the positivist approach to teaching and learning in medical education and medical settings that perpetuate a reductionist idea of a right or wrong method, that treatment is either cure or failure, or that emotions should not be acknowledged in an arguably a scientific process. Their Theory of Medical Education points to the benefits of adopting a constructivist approach, as opposed to the dominant positivist approach, to embedding medical knowledge. They suggest this would better allow for the lifelong consideration of individual difference, of values and beliefs, and the acknowledgment that learning can be a process of construction from previous experiences and the shared learning from observation within groups. They suggest that constructivist learning creates fewer opportunities for the perception of failure, or of hero. Understanding the psychological constructs that underpinning reluctance to deliver effective care, whether individual or systemic within medical education, is important for the development of better physicians, more effective teaching and learning within clinical courses and hospital settings, ultimately leading to interventions that could offset avoidance in medical treatment and enhance effective care.

### **Fear of Failure: A Theoretical Context**

FOF was initially defined as one's attempt to avoid feelings of shame or humiliation as a consequence of being unable to achieve a goal (Atkinson, 1957). The definition has been developed into a more cognitive-specific construct by Conroy (2001), as a cognitive protective response to the anticipation of a threat to one's ability or sense of worth, with the goal of avoiding any strong or difficult emotional reaction connected to the threat. Within clinical environments, FOF can lead medical professionals to develop strategies that

further enable avoidance; this may include aiming to avoid certain specialisms that may induce threat or panic (Prod'homme et al., 2018; Thiemann et al., 2018), even when this conflicts with their core values and hampers essential skill acquisition (Crowe & Brugha, 2018; El-Rouby et al., 2020; Whitehead, 2012) – a consistent theme across FOF research (Conroy & Elliot, 2004). Feelings of failure are elicited in clinicians when patients reject treatment, when negotiations fail, or when a patient's body no longer responds to treatment. Failure has been found to be shaped by social and cultural expectations of responsibility; coming both from clinician, peers in medical teams, and patients receiving support (Crowe et al., 2017; Economos et al., 2020; Prod'homme et al., 2018; St Ledger et al., 2021; Wolfreys, 2016; Zambrano et al., 2012). There may be a cyclical effect with FOF in healthcare settings; avoiding patient deaths and EOL discourse may further impede confidence and comfortableness within this area. Moreover, those who have more experience of patient deaths within specialisms that do not consider death a failure of treatment may also have a lower personal sense of FOF (Crawford & Zambrano, 2015).

In contexts outside of medicine, for example in business, sport, and education, where evaluation is considered fundamental to achievement, high FOF can be perceived to negatively influence physical capacity to endure stress, increase poor coping behaviours like eating disorders and drug abuse, and heighten negative psychological qualities, such as worry, depression, perfectionism, and antisocial behaviour (Sagar et al., 2007). These negative physical and psychological qualities extended beyond sporting performance to the individual's sense of wellbeing and functioning. In these disciplines, tools have been developed to influence failure cognitions, and develop greater opportunity for successful practice (Sagar et al., 2009).



Given EOL care can be characterised by effective communication and intervention, understanding this field may lead to greater experiences of care and wellbeing for patients in the last days and hours of life, and better outcomes for staff members involved in this care. Further, reducing stigma and perception of failure may also generate more open discussion about mistakes, thereby facilitating a more honest and open environment in healthcare and education settings.

### **The Current Study**

This research study aimed to investigate the role of fear and anxiety in EOL care, namely whether FOF influences a clinician's perception of their confidence and comfortableness with the delivery of EOL care. Furthermore, it also explores whether those who are more likely to encounter death in their workplace showed less FOF. It was recognised that other factors may affect EOL conversations, including role, gender, years of experience, and number of EOL conversations, so these covariates have been included in the analysis. The hypothesis was that individuals who score higher on the Performance Failure Appraisal Inventory (IV; PFAI; Conroy, Willow & Metzler, 2002) will show less confidence in how they communicate (DV1), less confidence in making decisions about death experiences (DV2), and less confidence in involving others in decisions (DV3) and will show higher levels of discomfort when working with people who are dying (DV4).

## Materials and Method

### Study Sample and Setting

This study adopted a cross-sectional quantitative design approach, using a homogenous stratified sample. The stratum subset was doctors and nurses, randomly selected through the distribution of a questionnaire to hospital teams.

For our planned analysis, sample size was calculated using the software GPower (Faul et al., 2007) based on the effect sizes found in a study examining the relationship between perfectionism and FOF in athletes ( $f^2$  = between 0.27 – 0.47; Sagar & Stoeber, 2009). However it was decided that a more conservative effect size would be more appropriate in this study's power analysis as it was a novel population being studied, and it was not clear whether the effect of FOF would be comparable between a population of athletes and the medical population being studied. Therefore a medium effect size of  $f = 0.15$  was utilised (alpha level = 0.05 and Power = 0.95, sample size = 89). Power was set to 0.95 to account for the need to run four regressions for each of the four dependent variables identified. See Appendix M for full analysis for both planned and exploratory analysis.

### Recruitment

An online anonymous questionnaire was distributed to doctors and nurses who had delivered EOL communication to patients in a trust in a major city in the North West of England, and a trust in the North East of England. A Covid-19 pandemic adaption to the research was to include other local and national networks known to the primary researcher. The distribution was supported by staff within the palliative, psychology, and R&D teams

within each of the two main hospital trusts who sent the link to the questionnaire out to hospital teams and managers, as well as through doctor and nurse online networks. A Freedom of Information request was made to each hospital to identify hospital data on teams / specialisms working in areas with a high prevalence of patient death, and this guided the distribution in the first instance. To encourage participation, £5 vouchers for an online retailer were offered to the first 85 participants, with funding for the vouchers provided by the Department of Clinical Psychology, University of Liverpool.

Invitation was sought to speak at these specialist team meetings and following this, the team leaders were emailed an anonymous link to send to their teams to complete the study if they wished, within their own time. Follow-up emails were sent to teams by the palliative care teams, and the trust R&D teams.

Although the focus of many comparative studies of EOL treatment has been on physicians, due to their ultimate decision-making responsibility within care proceedings, specialist nurses (defined as nurses working at band 6 and above) have been included in this study as they offer a broader level of care, which may encompass emotional support as well as additional decision-making responsibility (Álvarez-del-Río et al., 2013). Therefore, nursing management in both trusts were involved also in the distribution and follow up requests.

The study was opened at the start of March 2021. The study closed to recruitment in July 2021.

### **Inclusion Criteria**

- Doctors and specialist nurses who have worked with adult EOL patients.
- Those who have access to a computer or smartphone.
- Location: The two specified north NHS trusts, or other local and national networks.

### **Exclusion Criteria**

- Individuals who have not had an EOL conversation with a patient in their care.
- Clinicians working exclusively with children.
- Clinical staff who offer care support but who do not communicate information about EOL prognosis or who are not able to make autonomous decisions about patient treatment. Decision to include only band 6 nurses or above as a result.

### **Ethical Considerations**

Before the start of the study, approval was sought from the Doctorate in Clinical Psychology Research Committee, within the Department of Clinical Psychology, University of Liverpool, the sponsorship review panel within the University of Liverpool (sponsor ref: UoL001588), the relevant NHS HRA review board (IRAS ref: 289310), and the R&D departments in each partner trust (North West ref: SP0564; North East ref: 289310). All methods were performed in accordance with the relevant guidelines and regulations. Consent from participants was recorded online and held in a secure database.

Information about participation and the nature of the research was accessible online, at the start of each questionnaire, and participants were required to confirm they understood

the objectives of the research, the inclusion and exclusion criteria, their rights as participants, the voluntary nature of the study and the confidentiality of answers and data management before they were able to complete the study.

No person-specific identifiable data was captured and downloaded within the study.

Participants were offered a £5 Amazon voucher in exchange for completing the survey. This aspect required the collection of participants' email addresses, but this information was held on a separate database that was only accessible at the end of the study, when the vouchers were distributed. No further expenses were offered to participants or facilitators of the study.

### **Procedure**

Participants were asked to read an information sheet outlining the objectives of the research, the inclusion and exclusion criteria, their rights as participants, the voluntary nature of the study and the confidentiality of answers and data management. Following this, they were provided with a link to a Qualtrics online questionnaire designed by the researcher. Participants were asked to provide their consent and anonymously complete demographics information (including NHS trust, gender, role, area of specialism, years of experience, a frequency guestimate of how many EOL conversations they had had per month) and complete three standardised self-report questionnaires.

### **Measures**

The questionnaire contained three elements: the Self-Efficacy in Palliative Care scale (SEPC; as adapted by Mason and Ellershaw, 2004), the Thanatophobia Scale (TS; Merrill,

Lorimor, Thornby et al., 1998), and The Performance Failure Appraisal Inventory (PFAI; Conroy et al., 2002). The measures can be found in Appendix O, shown as part of the full questionnaire. The PFAI was the independent variable in the study analysis. The three subscales of SEPC were representative of dependant variables 1, 2, and 3. TS was representative of dependant variable 4.

### ***Confidence with EOL Care***

Measured using the Self-Efficacy in Palliative Care scale (Mason & Ellershaw, 2004), which assesses efficacy in three subscales: confidence in communication, confidence in decision making and patient management and confidence in multi-professional teamworking. The SEPC has 23 items, measured on a Visual Analogue scale from 'Very anxious' to 'Very competent' over 100 units (0-100). Participants are asked to make a mark on a line between these two points to indicate their selection. A mean score was calculated for each subscale.

### ***Comfortableness with EOL Care***

Measured using the Thanatophobia Scale (Merrill et al., 1998), which assesses attitudes towards palliative care. The TS is a seven-point ordinal scale containing seven items, including response options of 1 (strongly disagree) to 7 (strongly agree). A total score was calculated for each participant.

The SEPC scale and TS have been shown to be valid and reliable assessment scales within clinical staff populations, with Cronbach's alpha ranges of 0.84-0.85 and 0.92-0.95, respectively (Mason & Ellershaw, 2004).

Within this study, the SEPC and TS questionnaires each began with the statement:

‘Presented are a series of statements that relate to issues and experiences that may be encountered when working with someone in the end stages of life. When answering the questions, we would like you to imagine how you think you would feel in relation to the issues and situations presented.’

### ***Fear of Failure***

The Performance Failure Appraisal Inventory (PFAI; Conroy et al., 2002) is a multidimensional measure of FOF developed from a meta-theory of emotions, examining FOF as a function of person-environment interaction, rather than a trait or state or global experience. It comprises 25 items that measure five dimensions of threat appraisals associated with FOF: (1) fear of shame and embarrassment (FSE); (2) fear of devaluing one’s self-estimate (FDSE); (3) fear of having an uncertain future (FUF); (4) fear of important others losing interest (FIOLI); and (5) fear of upsetting important others (FUIO). The measure uses a five-point scale with response options of -2 (‘do not believe it at all’), 0 (‘believe it 50% of the time’), and +2 (‘believe it 100% of the time’). Within this study, all items are introduced with the phrase ‘In my medical practice...’.

Although the PFAI has been designed for use in North American sports populations, it has been validated in different languages and contexts. It has not, however, been validated within medical settings. Contact with the author of the measure confirmed that it should be suitable for use within this context as it is designed to assess a broad motivational disposition rather than context-specific motivation. Given that this is the first application of

the measure in this context, very little is known about the psychometric properties of scores on this measure in healthcare populations. Therefore, although not part of the primary research question of this paper, the internal consistency of the PFAI has been examined to ensure reliability and that the items represent the full construct of PFAI, with the aim of creating a platform for others to develop the use of the measure in the future. Given the recent problems uncovered with Cronbach's alpha, especially with small samples and potential non-normality (Trizano-Hermosilla & Alvarado, 2016), both Cronbach's alpha and McDonald's  $\omega$  will be presented.

### **Data Analysis**

A Mann-Whitney U test was used to look at the relationship between gender and the scores on the PFAI, SEPC and TS, excluding the results of the two participants who did not report a binary gender.

To test the hypothesis that people who score higher on the PFAI will show less confidence in how they communicate (DV1), make decisions (DV2) and work with others (DV3), and show higher levels of discomfort (DV4), a hierarchical regression was applied. Covariates were included in step 1 (gender, role, area of specialism, years of experience, and a frequency guesstimate of how many EOL conversations were had per month). Step 2 tested the potential relationships between FOF, as measured by the PFAI total score, and each dependent variable. A further exploratory analysis looked at the subscales of the PFAI measure against each variable, as well as including an additional DV, total SEPC score.

### **Data Storage**



Data was recorded, anonymised, and contained within the online Qualtrics platform. The anonymous data was then transferred for formatting using Microsoft Excel, and analysis using statistics software Jamovi (Jamovi Project, 2021).

## Results

### Descriptive Statistics

A total of 306 individuals took part in the study. Of these, 205 responses were included for analysis, with the remainder excluded due to not meeting eligibility criteria or submitting incomplete data.

As can be seen from Table 1, there was almost an equal mix of doctors and nurses in the sample and the majority of responses were from the North West NHS Trust. When compared with workforce numbers accessed through a FOI request for The North West NHS Trust and the North East NHS Trust, 2.8% of the eligible workforce within the North West NHS Trust and 2.3% of those in the North East NHS Trust completed the questionnaire, indicating a proportionate representation across the sample.

As Table 1 shows, the total sample was skewed towards female respondents. Across all participants, 85 out of 101 (84%) of the nursing sample were female, and for doctors, 63 (61%) were male, and 40 (39%) were female, which is reflective of the gender distribution in the healthcare workforce in the UK (Kings Fund, 2018).

**Table 1**

*Frequencies of participants by NHS trust, role, and gender*

NHS Trust	Count	% of total	Role			Gender distribution		
				Count	% of total	Male	Female	Do not wish to disclose
North West NHS Trust	86	41.9%	Doctor	43	20.97%	31	12	0
			Nurse	43	20.97%	8	35	0
North East NHS Trust	58	28.4%	Doctor	29	14.1%	17	11	1
			Nurse	29	14.1%	5	24	0
Other NHS Trust	61	29.9%	Doctor	32	15.6%	15	17	0
			Nurse	29	14.1%	2	26	1
Overall Total	205		Doctors	104	50.7%	78 (38%)	125 (61%)	2 (0.97%)
			Nurses	101	49.3%			

Most respondents from the North West NHS Trust had between 5-10 years' experience (n=31, 36%), followed by 3-5 and 10-15 years (n=14, 16% for each category; Figure R1, Appendix R). In the North East NHS Trust, the results were more evenly spread across the sample, with the majority having 10-15 years' experience (n=14, 24%) followed by 5-10 years (n=13, 22%), and 15-30 years (n=10, 17%). Responses from local and national networks outside of these trusts had much less experience comparatively, with the majority having 1-3 years' experience (n=17, 28%), followed by 3-5 years (n=11, 18%) and 5-10 years (n=10, 16%). There was no significant gender difference in the number of years of experience reported ( $U= 4873, p=0.996$ ).

When looking at how years of experience relates to EOL conversations per month, in general, there was a positive correlation between years of experience and EOL conversations had. The most frequently reported number of EOL conversations for people with between 0-3 years' experience was between 1-2 conversations per month. People with

between 3-15 years' experience most frequently reported 2-5 conversations per month.

This figure jumps to more than 12 conversations per month for people with between 15-30 years of experience but reduces again for those with 30+ years' experience, who reported 1-3 conversations per month.

Participants were asked about their areas of specialism to give an indication of sample and response rate distribution across hospital specialism areas (Table 2). Fifteen % of participants (n=30) did not state their clinical speciality. The specialisms with the largest response rate included Oncology (n=26, 12.7%), Cardiovascular medicine (n=25, 12.2%), and Palliative medicine (n=21, 10.2%). Although these groups were targeted for distribution due to their high ward death rates, according to FOI requests, which may explain a greater response rate than some other clinical specialisms, other targeted specialisms did not show the same level of response, including Geriatric medicine (n=11, 5.4%) Endocrinology (n=1, 0.5%) and Haematology (n=13, 6.3%).

**Table 2**

*Distribution of sample clinical specialties across participants, organised by trust and role*

		Specialties / departments																			
		Cardiovascular	Critical Care	Emergency Medicine	Endocrinology	Ear, Nose and Throat	Gastroenterology	General medicine	Geriatric medicine	Haematology	Hand surgery	Head and Neck	Internal medicine	Neuro medicine	Obstetrics and Gynaecology	Oncology	Orthopaedics	Palliative medicine	Stroke	Other	Unknown
North West NHS Trust	Doctors	6	0	7	0	1	4	1	2	3	0	0	5	1	1	3	1	0	1	1	6
	Nurses	3	2	6	0	0	0	2	3	4	0	0	1	2	1	0	1	2	0	2	14
	<b>Total</b>	<b>9</b>	<b>2</b>	<b>13</b>	<b>0</b>	<b>1</b>	<b>4</b>	<b>3</b>	<b>5</b>	<b>7</b>	<b>0</b>	<b>0</b>	<b>6</b>	<b>3</b>	<b>2</b>	<b>3</b>	<b>2</b>	<b>2</b>	<b>1</b>	<b>3</b>	<b>20</b>
North East NHS Trust	Doctors	7	0	0	0	1	1	3	2	2	0	0	3	1	0	0	2	2	1	0	4
	Nurses	3	0	0	0	0	1	2	1	1	1	1	2	1	0	6	0	8	0	1	1
	<b>Total</b>	<b>10</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>5</b>	<b>3</b>	<b>3</b>	<b>1</b>	<b>1</b>	<b>5</b>	<b>2</b>	<b>0</b>	<b>6</b>	<b>2</b>	<b>10</b>	<b>1</b>	<b>1</b>	<b>5</b>
Other NHS Trust	Doctors	1	1	0	1	0	0	1	3	2	0	0	1	0	1	13	2	4	0	1	1
	Nurses	5	9	0	0	0	1	0	0	1	0	0	0	0	0	4	0	5	0	0	4
	<b>Total</b>	<b>6</b>	<b>10</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>1</b>	<b>3</b>	<b>3</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>17</b>	<b>2</b>	<b>9</b>	<b>0</b>	<b>1</b>	<b>5</b>
<b>Total across Trusts</b>		<b>25 (12%)</b>	<b>12 (6%)</b>	<b>13 (6%)</b>	<b>1 (0.5%)</b>	<b>2 (1%)</b>	<b>7 (3%)</b>	<b>9 (4%)</b>	<b>11 (5%)</b>	<b>13 (6%)</b>	<b>1 (0.5%)</b>	<b>1 (0.5%)</b>	<b>12 (6%)</b>	<b>5 (2%)</b>	<b>3 (1%)</b>	<b>26 (13%)</b>	<b>6 (3%)</b>	<b>21 (10%)</b>	<b>2 (1%)</b>	<b>5 (2%)</b>	<b>30 (15%)</b>

## Differences Between Groups

There was not a significant effect found for gender on the PFAI nor the Self-Efficacy scale (SEPC) total score or subdomain scores. There was, however, a significant effect for gender ( $U= 3057, p<.001$ ) on the Thanatophobia scale (comfortableness with death) with male respondents feeling less comfortable with death ( $M = 24.6, SD = 9.78$ ) compared to female respondents ( $M= 18.2, SD =9.26$ ; Figure R2, Appendix R). Cohen's effect size value ( $d=.37$ ) indicates a moderate to large practical significance.

There was no significant difference between doctors' and nurses' scores on the FOF and Self-Efficacy measures, but a difference was found on the Thanatophobia scale ( $U=3579, p<.001$ ), with doctors reporting higher levels of discomfort with death ( $M = 23.29, SD = 9.76$ ) than nurses ( $M = 17.99, SD = 9.31$ ; Figure R3, Appendix R). Cohen's effect size value ( $d=.56$ ) indicates a large practical significance.

## Internal Consistency Reliability Analysis

The PFAI subscales consisted of 25 items and were found to be highly consistent across all items ( $\alpha = 0.920; \omega = 0.921$ ), indicating it is an effective measure when measuring medical populations. The strength of relationship between subscales of the PFAI is shown can be found in Figure R4 (Appendix R).

## Multiple Linear Regression

### *Planned Analysis*

A hierarchical regression analysis was conducted to analyse the effect of participants self-perceived confidence in clinician communication with patients at the EOL (DV1) on

perceived FOF (Table 3). Step 1 included the covariates gender, role, years of experience, and number of EOL conversations per month, and FOF was added as the second step. Covariates accounted for 8.2% of the variance in confidence in clinician communication although only estimated number of EOL conversations per month was a significant predictor, with confidence in communication higher for those who had more EOL conversations. The addition of step 2, the Fear of Failure score, reduced the amount of variance accounted for by the model by 0.4% to 7.8%. However, the regression coefficient was not significant.

For DV2, confidence in clinician decision making, covariates in step 1 accounted for 8.8% of the variance in confidence with decision making with patients at the EOL although estimated number of EOL conversations per month was the only significant predictor, with confidence in decision making higher for those who had more EOL conversations. The addition of step 2 reduced the amount of variance accounted for by the model by 0.26% to 8.54%. However, the regression coefficient was not significant.

For DV3, confidence in working with others, neither model was shown to be a good fit for the data.

For DV4, a clinician's comfortableness about providing EOL care, covariates in step 1 accounted for 11.6% of the model variance in a clinician's comfortableness with death. Gender, role, and estimated number of EOL conversations per month the three significant predictors within this model, with men less comfortable with death than women, and doctors less comfortable than nurses, and those who had more conversations per month were less uncomfortable with EOL work. The addition of step 2 increased the amount of

variance accounted for by the model by 0.3%. However, the regression coefficient was not significant.

**Table 3**

*Regression analysis showing gender, role, years of experience, number of EOL conversations, and FOF, as predictors of the four dependant variables*

Dependant variable	Predictor variable	Cumulative		Simultaneous	
		R <sup>2</sup>	F	β	p
Perceived confidence in communication (DV1)	Step 1				
	Gender	0.082	F (4,198) = 5.53, p<.001	3.585	0.350
	Role			2.072	0.583
	Yrs. of Experience			0.510	0.628
	No. EOL conversations per month			4.654	<.001
	Step 2				
	Fear of Failure score (PFAI)	0.078	F (5,197) = 4.41, p<.001	0.399	0.848
Perceived confidence in decision-making (DV2)	Step 1				
	Gender	0.088	F (4,198) = 5.87, p<.001	3.025	0.378
	Role			0.523	0.877
	Yrs. of Experience			-0.845	0.369
	No. EOL conversations per month			4.625	<.001
	Step 2				
	Fear of Failure score (PFAI)	0.0854	F (5,197) = 4.77, p<.001	1.226	0.509
Perceived confidence in working with others (DV3)	Step 1				
	Gender	0.024	F (4,198) = 2.22, p=0.068	3.233	0.388
	Role			1.268	0.731
	Yrs. of Experience			-0.481	0.639
	No. EOL conversations per month			2.951	0.007
	Step 2				
	Fear of Failure score (PFAI)	0.019	F (5,197) = 1.77, p=0.120	0.227	0.155
Perceived comfortableness with EOL care (DV4)	Step 1				
	Gender	0.116	F (4,198) = 7.65, p<.001	-4.560	0.003
	Role			-3.663	0.016
	Yrs. of Experience			0.313	0.458
	No. EOL conversations per month			-0.876	0.050
	Step 2				
	Fear of Failure score (PFAI)	0.113	F (5,197) = 6.13, p<.001	0.347	0.677

Further statistical output can be found in Table P1 (Appendix P).

### ***Exploratory Analysis***

Whilst a total PFAI FOF score did not, generally, increase the amount of variance accounted for by the model, further exploratory analysis demonstrated that individual subscales of PFAI did show some significant relationships with the dependent variables (Table Q1, Appendix Q).

For DV1, when controlling for the four covariates, step 2 accounted for an additional 9.8% of the variance in confidence in EOL conversations, from 8.3% in step 1 to 18.1% in step 2. The regression coefficient associated with PFAI subscale 'Fear of Experiencing Shame & Embarrassment' (FSE) suggests that as each unit of FSE increases, confidence in communication also increases by approximately 3 units. The regression coefficient associated with PFAI subscale 'Fear of Important Others Losing Interest' (FIOLI) suggests that as each unit increases, confidence in communication decreases by approximately 7 units.

For DV2, when controlling for the four covariates, step 2 accounted for an additional 5.8% of the variance in confidence in EOL decision-making, from 8.9% to 14.7%. The regression coefficient associated with PFAI subscale 'Fear of Devaluing One's Self-Estimate' (FDSE) suggests that as each unit of FDSE increases, confidence in decision-making decreases by approximately 8 units.

For DV3, the model was not found to be a good fit for the data. For DV4, the regression coefficients explored for step 2 were not significant.



For SEPC total, the total score from the self-perceived efficacy in palliative care scale, step 1 accounted for 8.2% of the variation in perceived self-efficacy delivering EOL care. Estimated number of EOL conversations per month was the only significant factor within this model, suggesting people who had more conversations had a higher sense of perceived self-efficacy. Step 2 increased the proportion of the variance accounted for by the model by 7.3%, to 15.5%. The regression coefficient associated with PFAI subscale Fear of Devaluing One's Self-Estimate suggests that as each unit of FDSE increases, total self-efficacy decreases by approximately 6 units.

## Discussion

This study has identified that FOF as a general concept, as defined by the PFAI, was not shown to have an impact on a doctor's or nurse's perceived ability to deliver effective EOL care. Contrary to the hypothesis, after controlling for gender, role, years of experience, and number of EOL conversations per month, FOF did not impact confidence in communication, decision-making, team working and comfortableness with EOL care. Estimated numbers of EOL conversations per month impacted all four of the variables measured, and gender and role had an additional impact on how comfortable a clinician was with EOL care and death. The study has also validated the use of the PFAI and its subscales within a new population group – medical professionals.

However, further exploratory analysis found that the subscales of the PFAI did show significant relationships with the dependent variables. A clinician who fears the loss of interest in them and their professional opinion was shown to negatively impact a clinician's confidence in communicating with patients. 'Fears of devaluing one's self-estimate', which looks at self-depreciation, blaming lack of talent or intellect for the situation, and disappointment in self, was found to negatively impact confidence in decision-making, working with others, and total self-efficacy. Interestingly, higher levels of 'fear of shame or embarrassment' increased confidence in communication, which is consistent with shame research suggesting that shame is a short-term motivator but is linked to long-term consequences like lower resilience and low mood (Zhang et al., 2018).

Working with others was impacted by the FOF subscale Fear of Devaluing One's Self-Estimate, which is consistent with the literature suggesting that some professionals are reluctant to engage and work with palliative care teams in the care of their patients, due to the fear that this indicates the failure of their treatment (Economos et al., 2020; St Ledger et al., 2021). Given there were not more relationships shown with other FOF subscales, this might indicate that the 'working with others' questions on the SEPC scale do not accurately measure a person's likelihood to engage with a palliative care team, but rather their confidence if they happen to work with other teams. Further, if a clinician is resistant to accepting that death is approaching, they may not consider a referral to a palliative service appropriate, and therefore it would not be considered a reluctance, but instead related to an inaccurate belief in their ability. It could also relate to therapeutic nihilism, and a belief that another service would be no more effective than current treatment, which has been highlighted most recently in the field of geriatric oncology (Biskup et al., 2019). There may also be a social bias related to reporting a reluctance to work with others, especially in settings or specialisms that promote or are guided toward MDT working (Sawyer et al., 2021).

A further unexpected result was in relation to who has EOL conversations most frequently. Within this study sample, relatively few junior staff have EOL conversations, with the overwhelming majority delivered by people with between 15 and 30 years of experience. Based on the literature reviewed, which reported that senior colleagues often ask junior colleagues to have EOL conversations on their behalf (Donnelly & Walker, 2021; Horlait et al., 2016), that junior doctors feel unsupported, over relied on, and sometimes judged by their senior colleagues (Nordenskjöld et al., 2020), and that very few saw positive examples

of EOL conversations being delivered (Crawford et al., 2021; Zambrano et al., 2012), it would be expected that more junior staff would report having EOL conversations, and fewer senior members of staff would report having EOL conversations. However, this discrepancy with the data presented could be explained by an overestimation by senior clinicians of their engagement with EOL patients or by a reluctance of senior clinicians to be observed by others, perhaps related to fear of criticism if not a FOF. The literature may, however, also simply describe one of the limitations of the hospital environment, in that there are too few clinicians available to meet all the demands of the role as well as to offer shadowing or observation experiences, or that it may not be considered appropriate to have observers present. The study shows that, by whatever means possible, more support from others, including frequent patient contact and engagement, improves clinical skills over time. This is in line with consumer feedback research that suggests engaging with patients and inviting feedback increases general and physiological knowledge, increases psychosocial content in patient interviews, reduces fear of patient engagement and criticism over time, and improves exam performance in medical students (Finch, Lethlean, Rose et al., 2018). It supports the findings that engaging with patients to communicate difficult messages, and to work alongside them in often challenging decision making may have a dual advantage in improving clinical skills and increasing opportunity and capacity for emotional experience.

There was a higher reported level of discomfort with death in physicians, particularly male physicians, rather than nurses and female physicians, but all showed some level of discomfort. Gender has often been linked in research with reluctance to talk about death, although it appears little research exists that focuses and explores specifically clinical staff experience in acute hospitals. Men have been shown to be more likely to develop distress

symptoms like depression and grief anxiety if they fail to make meaning out of loss experience (Stelzer et al., 2019). Men are also shown to be less expressive of grief and confide less in others compared to female counterparts (Stroebe et al., 2001). It is possible that men and women are more similar than different in terms of many aspects of psychological processing (Hyde, 2005) and, according to social role theory (Eagly et al., 2000), they may simply get fewer opportunities for social support, in turn learning fewer ways to express emotion, or are less familiar with being forthcoming about emotional experience, and the benefits of vulnerability and social support. Given that many senior clinicians having EOL conversation were male physicians, one could assume that this target group may be less likely to want to encourage observation and peer learning or may be more impacted by the psychological FOF factors identified in this study.

Theories of medical education may be able to explain some of the study findings. Within the regression analysis, variance was low suggesting the respondent results were largely similar. Given traditional medical education has often taken a positivist position, participants educated from this perspective may largely dismiss the role emotions play in objective decision making, and therefore may be less likely to show an awareness of how events have affected them and their practice (Mann, Dornan & Teunissen, 2011). Further, the validity of using self-report questionnaires within this population may also present a risk of bias, given that it is affected by what the participant perceives the goals of the measure to be (Van de Mortel, 2008). Judgement about how to respond may have been affected firstly by how emotions have been welcomed or dismissed in the past, secondly the participants perceived value of emotions, both patient and self, as contributing to good medical practice, and thirdly how self-report measures have been used across their education to assess their skills

and abilities. Participants may have considered the questionnaire an exercise in assessing competence rather than considering it a measure of emotional experience. The wording of the SEPC questionnaire encourages participants to imagine how they would feel in relation to the issues and situations presented, but this could have been interpreted as how one 'should' feel, especially if their education and environment emphasises performance and is critical of mistakes or swaying from imposed practice structures (Mann, Dornan & Teunissen, 2011). Further, if emotions are not considered a valuable form of knowledge, an emotional disconnect could occur, sanitising emotions into a set of behavioural skills, perhaps providing a greater illusion of objectivity (Shapiro, 2011).

There continues to be debate about the most effective approach to medical education, and recent literature reviews remain unclear about whether there is a 'best way' to provide teaching about palliative care to medical professionals (Boland, Brown, Duenas, Finn & Gibbins, 2020). Despite changes to curriculum and teaching methods, graduates report feeling unprepared to provide EOL care, and anxiety continues to be a common theme (Walker, Gibbins, Barclay et al. 2016). Simulation-based learning, greater interprofessional team working, and learning from patient experience are all methods that are being explored to increase the connection between patient and clinical staff (Latta & MacLeod, 2019). It may be beneficial to explore whether different medical education approaches affect self-report studies looking at emotional experience. Understanding how questions about emotional experience are understood by participants may help to appreciate the impact that education, environment, and context have on learning, as well as the lifelong legacy of medical teaching methods in how clinical events are processed.

In line with the literature, there may have been some reluctance from some specialties in completing the EOL questionnaire. Haematology has been previously identified as a specialty that 'treats until the end' and engagement with palliative teams seen as a sign of 'giving up' (Prod'homme et al., 2018). Despite the deliberate push to recruit from these teams, and the primary researcher presenting at several senior team meetings, they were not as responsive as other targeted groups. Other specialties that have very high death rates were also unexpectedly low in terms of response rate. Geriatric medicine and endocrinology are not often identified in literature as specialties that experience reluctance; geriatric medicine reportedly works very closely with palliative care teams given the age of their population (Lenherr et al., 2012). It may be that several factors influence response rates, including the Covid-19 pandemic with stretched healthcare staff with less availability to complete the study and the movement of doctors and nurses into specialties that were not familiar to them to meet the demand of the pandemic. The response rate for specialty may also not account for specialties that have smaller teams, rather than a reluctance in these groups to engage. Unfortunately, the FOI request on eligible workforce numbers from trusts did not break the figures down by specialisms, so further analysis to explore this area was not possible.

The data for this study was collected during the Covid-19 pandemic, which was timely given the distressingly high death rates in the UK and globally, and the united effort of clinicians from all disciplines in the management of very unwell patients. Many practitioners unfamiliar or less inclined to engage with EOL processes have been required to utilise these skills, and this may have been one of the factors that positively impacted the rate and enthusiasm of response to this study and the diversity of respondents. It may also

demonstrate clinicians' current desire to have opportunities to reflect on their experience of EOL care and the factors influencing confidence, comfortableness, and reluctance.

### **Strengths and Limitations**

As described by Conroy (2001), FOF can be viewed as a cognitive protective response to the anticipation of threat to one's ability or sense of worth, with the goal of avoiding strong or difficult emotions. These same processes could have impacted the honest reporting of fears of failure, or may have contributed to cognitive dissonance, especially in relation to such a sensitive and often avoided topic and could explain why the general FOF score was unable to produce a significant relationship with the SEPC and TS scales.

Replicating this study but comparing FOF with a less sensitive topic may be helpful in identifying whether this measure is effective in this clinical population. Increasing the number of participants and perhaps limiting the study to a single medical role, may clarify any non-significant results. The self-report measures used did not measure confidence in embracing patient feedback. Embracing patient feedback has been found to increase competence as well as enhance clinician engagement with emotion in self and others (Finch, Lethlean, Rose et al., 2018), and so exploring other measures that could consider a clinician's engagement with consumer feedback could be a valuable addition. Using self-report measures may not, however, capture the reality of practice given that both conscious and unconscious social biases influence responses. Observation studies running alongside self-reports can identify discrepancies in reporting and ensure that these are accounted for in subsequent analyses. In-depth interviews may help illuminate whether cognitive dissonance is indeed a limiting factor in questionnaire studies in this area.



The unexpectedly positive response to this study may indicate the need for space to reflect about EOL processes and the psychological factors that impact them, perhaps created, or propelled, by the pressure on clinicians to support EOL patients during the Covid-19 pandemic. Further development of this project would be to compare the responses captured in this study with a period in the future where the healthcare system is under less pressure in relation to dying patients, and to reflect on the impact of acute periods of death on how EOL processes are perceived. Further, given there may be a cyclical effect where avoidance impedes confidence and comfortableness within this area, targeting specialties that reportedly present a culture of treating an illness up to the EOL, and comparing their response with other specialties may be useful in identifying whether belief in ability to cure shares similarities with avoidance to acknowledge the reality of death.

Wider application of the PFAI to explore the emotional experience of healthcare workers would further validate its application to this population group and help with the reliability of the measure. However, the study clearly identifies that other psychological factors are likely to play a role in reluctance in EOL processes, and concepts like power, hierarchy, and the anticipation of judgement and criticism could be impacting the care of patients at the EOL and should be explored in further studies.

There are several strategies that exist for managing fear and anxiety that have emerged from FOF studies in other settings, and the exploratory findings of this study indicate that it may be valuable to explore the use of these strategies within medical populations.

Avoidance-focused strategies, like forms of mindfulness, have been found to be a positive

strategy when EOL rumination is knowingly affecting decision-making within the moment, but relies on creating space for post-event processing (Rodenbach et al., 2016). Schwartz rounds are an example of spaces in health settings designed for sharing and reflection, that have been found to be effective in reducing shame and acknowledging difficult health situations (Flanagan et al., 2020). Emotion-focused coping strategies like positive-self talk, positive reinterpretation, lowering goals, seeking emotional support, and problem focused strategies, such as increasing effort and education to prevent failure, and confronting salient fears, have also been found to be effective strategies (Amati & Hannawa, 2014; Crawford et al., 2021).

### **Clinical Implications**

By understanding the factors impacting EOL care, more can be done to reduce their negative effects, and consequently positively impact patient care. Psychology has a unique opportunity to educate and support medical teams to understand and manage psychological processes, and to promote the role that safe and accepting supervision and social support can have on the development of empathy. Psychology can also offer better ways of preparing oneself before giving difficult and complicated messages to patients and managing the resulting effects of self and social perception, drawing from existing literature developed by other psychological disciplines that already have extensive knowledge and practice of working with FOF.

Therefore, further work developing from this research could include studies to look at how to increase familiarity with EOL working for less confident staff, to explore strategies used by those who report less FOF, and to investigate effective fear-reducing strategies identified

in other FOF literature from Occupational Psychology, Sports Psychology and Educational Psychology.

Finally, this research has shown that modelling effective care from senior to junior colleagues is important to reduce negative social perceptions around vulnerability, exposure, weakness, and failure. It is important that an investment into support for managing the psychological factors that impact clinical practice is not limited to medical or nursing students, but is also offered to senior staff members who are tasked with modelling good practice to junior colleagues. Education and support should be promoted at all levels of healthcare, including within leadership.

Whilst FOF is likely to be one psychological process affecting the delivery of EOL care, this study has demonstrated that it does not explain all the variance in how confident and comfortable a clinician feels about delivering EOL care. Therefore, there remain a number of unknown psychological factors affecting the delivery of EOL, and this offers a platform for the development of further research in this area.

## **Conclusion**

Overall, this study has shown that FOF as a general concept, as measured by the PFAI, is not representative of a single psychological factor impacting clinicians working in EOL care. Notwithstanding, three of the five subscales of the PFAI measure did represent some of the psychological factors that impacted clinician delivery of EOL care. Despite significance, the models still only accounted for up to 18% of the data, indicating that other variables outside these factors are likely impacting the delivery of EOL care.

We have demonstrated that psychological factors have an impact on a clinician's confidence and comfortableness with EOL conversations with patients and colleagues, and EOL decision-making. By understanding FOF in the context of EOL care, hospitals may be able to improve outcomes for patients. The scale and diversity of the sample, the validation of a new measure to capture clinician emotional experience, and the robust analysis using a two-step multiple linear regression, has demonstrated links between aspects of FOF and barriers clinicians face in confidence related to communication, decision-making and comfortableness with EOL processes. Given FOF is an undeveloped psychological construct within this population, this research opens opportunity for further exploration, including how aspects of FOF develop, sustaining factors, and other areas of clinical practice that FOF impacts. It also creates opportunity to bring several research fields together, including research from business, education, and sport, that have already been developing the research base and exploring the impact of FOF on performance. Techniques that have been developed to offset the negative effects of FOF for other populations can now be researched and potentially applied to this medical population to see whether the same positive effects can be observed.

## Declarations

Consent for publication - All the authors mentioned in the manuscript have agreed to authorship, read, and approved the manuscript, and given consent for submission and subsequent publication of the manuscript.

Availability of data and materials - All data analysed for this study is included in this published article as a supplementary information file. Data has been deposited at the following Data Catalogue DOI: [10.17638/datacat.liverpool.ac.uk/1651](https://doi.org/10.17638/datacat.liverpool.ac.uk/1651)

Competing interests - The results/data/figures in this manuscript have not been published elsewhere, nor are they under consideration by another publisher. All the material is owned by the authors and/or no permissions are required.

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Authors' contributions - John Latham wrote the main manuscript text. All authors, John Latham, Sarah Butchard, and Stephen Mason, reviewed the manuscript.

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## Appendices

## Appendix A

**Table A1**

### Systematic Review Search Strategy

Search	Results	Terms / limits used	Comments
First search	Scoping: Google scholar 11.06.2020–19,800 results	Search term: 'physician fear and effective end of life communication medical communication and decision-making' Limits – date of publication from 1985 to current	Too many – unreliable strategy
Second search	Scoping: Google scholar 11.06.2020–19,500 results	Search term: 'fear' replaced with 'emotions' in above title Above limits same.	Too many- unreliable strategy
Third search	Scoping: PubMed (11. 06.2020) – 86,809 results	Developed a list of all possible search terms I could think of. All search terms together in the advanced search section. (fear*[Mesh] OR emotions [tiab] OR thanatophobi*[tiab] OR anxiet*[tiab] OR death attitude*[tiab] OR attitude*[tiab] OR death attitude*[tiab] OR avoidance[tiab] OR anxiety [tiab] OR distress[tiab] OR death salienc*[tiab] OR death orientation*[tiab] OR patient death [tiab] OR own mortality[tiab] OR failure [tiab] OR Worr*[tiab] OR panic*[tiab] OR terror*[tiab] OR dread*[tiab] OR horror[tiab] OR feelings [tiab]) AND ("Health personnel"[Mesh] OR "Attitude of health personnel"[Mesh] OR "Education, Professional"[Mesh] OR health care worker*[tiab] OR health care profession*[tiab] OR "health care staff"[tiab] OR physician*[tiab] OR medical speciali*[tiab] OR Physician*[tiab] OR general practitioner*[tiab] OR surgeon*[tiab] OR "GP"[tiab] OR nurs* [tiab] OR oncologist*[tiab] OR geriatri*[tiab] OR internist*[tiab] OR gynaecologist*[tiab] OR gynecologist*[tiab] OR obstetrician*[tiab] OR intensivist*[tiab] OR neurologist*[tiab] OR paediatrician*[tiab] OR pediatrician*[tiab] OR cardiologist*[tiab] OR pulmonologist*[tiab] OR orthopaedic*[tiab] OR orthopedic*[tiab] OR urologist*[tiab] OR nephrologist*[tiab] OR resident[tiab] OR residents[tiab] OR residency[tiab] OR residencies[tiab] OR house staff*[tiab] OR medical staff[tiab] OR medical educati*[tiab] OR health professional*[tiab] OR hospice medicine[tiab] OR hospice care[tiab] OR palliative medicine[tiab] OR palliative care[tiab] OR death education*[tiab] OR caregiver*[tiab] OR care provider*[tiab] OR clinician*[tiab] OR infectiologist*[tiab] OR infectologist*[tiab] OR Haemo* [tiab] OR specialist [tiab]) AND ("Communication"[Mesh] OR "Physician patient relations"[MeSH] OR "Advance care planning" [MeSH] OR "Decision making"[Mesh] OR "end of life care"[Mesh] OR communication[tiab] OR communicating[tiab] OR consultation*[tiab] OR conversation* OR dialog*[tiab] OR "patient provider"[tiab] OR "provider patient"[tiab] OR "Physician patient"[tiab] OR "patient Physician"[tiab] OR "Physician client"[tiab] OR "client Physician"[tiab] OR "physician patient"[tiab] OR "patient physician"[tiab] OR advance care plan*[tiab] OR advanced care plan*[tiab] OR treatment*[tiab] OR medical decision*[tiab] OR "medical care"[tiab] OR "decision making"[tiab] OR caring[tiab] OR end of life decision*[tiab] OR "end of life care"[tiab] OR (discuss*[tiab] AND resuscitation*[tiab]) OR "quality of life"[tiab] OR "death notification"[tiab] OR end of life discussion*[tiab] OR code status discussion*[tiab] OR caring for dying patient*[tiab] OR care of the dying[tiab] OR therap*[tiab] OR "breaking bad news"[tiab] OR advance directive*[tiab] OR advanced directive*[tiab] OR "patient care"[tiab] OR patient death[tiab])  Limits: - Language: English - Date of publication: from 1 Jan 1985	Too many- unreliable strategy
Fourth Search	Scoping: Pubmed – 12.06.2020 – 3,670,560	Searching each category of search terms separately, starting from Physician-patient / communication / decision making category Same limits as above.	Too many – unreliable strategy
Fifth search	Scoping Medline - New terms – 10.02.21 – 621	621 combined results for (1 AND 2 AND 3 AND 4 AND 5): ~"(((Physician* OR physician* OR "specialist nurs*"),ti,ab AND (patient* OR "service user*"),ti,ab) AND ("end of life" OR palliative).ti,ab) AND (conversation* OR communicat* OR decision*).ti,ab) AND (barrier* OR challenge* OR restriction* OR impediment*).ti,ab"  Decision to remove items to broaden search: (failure OR fear OR anxiety OR shame OR Feel* OR affect OR avoidance).ti,ab	To continue
Sixth search onwards	Repeated for PsycINFO (238), PubMed (851), BNI (155), and CIAHL (423). 10.02.21	Imported into endnote to identify duplicates –10.02.21 – 2288 total articles, 4 exact matches = 2284 (Rayyan). 1707 duplicates found on Rayyan – 1137 on Endnote. Number of references after duplicates excluded: 1630 Inclusion / Exclusion criteria established Review checklist – See Draper additional doc for framework.	Identified that some notable (Draper et al., 2019) papers had not been included in search – decision to re-run searches excluding 'patient' or 'service user', to broaden search.

Search	Results	Terms / limits used	Comments
<b>Seventh search</b>	23.02.21: MEDLINE (713), PsycINFO (282), PubMed (1095), BNI (186), CINAHL (491).	-	-
<b>Eighth search</b>	9488 papers in total were identified across all five databases (Medline – 3882; PsycINFO – 1543; PubMed – 6236; BNI – 958; CINAHL – 2469).	25.02.21 – as key Draper et al. paper did not come up until without the predetermining elements removed: (barrier* OR challenge* OR restriction* OR impediment*).ti,ab" Without the above elements, and using the following terms: "((Physician* OR physician* OR "specialist nurs*").ti,ab AND ("end of life" OR palliative).ti,ab) AND (conversation* OR communicat* OR decision*).ti,ab"	Considering Draper search processes – included 'attitude' and other similar words, identified through a thesaurus). Refined to the following terms following a scoping exercise: (perspective* OR perception* OR attitude* OR view* OR approach* OR belief* OR opinion*).ti,ab
<b>Final search terms</b>	Medline- 2072; CINAHL – 1343; PsycINFO- 875; PubMed – 3694; BNI – 516. Total:8429.	"(((Physician* OR physician* OR "specialist nurs*").ti,ab AND ("end of life" OR palliative).ti,ab) AND (conversation* OR communicat* OR decision*).ti,ab) AND (perspective* OR perception* OR attitude* OR view* OR approach* OR belief* OR opinion*).ti,ab"	Moved into Endnote, and then to SR-Accelerator for more accurate deduplicating. Manually deduplicated all records. Number of duplicates removed 3827. Transferred to Rayyan and a further 316 duplicates identified. Number of papers included for title and abstract screening: 4286

## Appendix B

**Table B1**

*Excluded USA Studies*

Paper title:	Paper 4: Sudden Advanced Illness: An Emerging Concept Among Palliative Care and Surgical Critical Care Physicians	Paper 6: Identifying barriers to psychosocial spiritual care at the end of life: A physician group study	Paper 11: Medical residents' perspectives on discussions of advanced directives: can prior experience affect how they approach patients?	Paper 14: Moral Distress Amongst American Physician Trainees Regarding Futile Treatments at the End of Life: A Qualitative Study	Paper 21: Approach to Palliative Care Consultation for Patients with Malignant Bowel Obstruction in Gynaecologic Oncology: A Qualitative Analysis of Physician Perspectives	Paper 24: A Qualitative Study of Oncologists' Approaches to End-of- Life Care	Paper 37: Relationships between personal attitudes about death and communication with terminally ill patients: How oncology clinicians grapple with mortality	Paper 39: Questioning Care at the End of Life	Paper 42: Barriers to Conservative Management Conversations: Perceptions of Nephrologists and Fellows-in- Training
Reviewed by:	JL	JL	JL	JL	JL	JL	JL	JL	JL
First author:	Barnett M D	Chibnall J T	Deep K S	Dzeng	Hoppenot C	Jackson V A	Rodenach R A	Ruopp P	St Clair Russell J
Year of publication:	2016	2004	2007	2015	2020	2008	2016	2005	2021
Country:	USA	USA	USA	USA	USA	USA	USA	USA	USA

*Note.* Excluded studies from USA that met all other inclusion criteria but have not been considered in the data extraction and review.

## Appendix C

### Systematic Review Data Extraction and Quality Method

Data extraction and quality method informed by Polanin et al (2019) and Draper et al. (2019), the Consolidated Criteria for Reporting Qualitative Studies (COREQ; Tong et al., 2007) as well as the Clinical Appraisal Skills Critical Appraisal Skills Programme (CASP; 2019) Qualitative Checklist. The content of the checklists are below.

#### Figure C1

##### *CASP Quality Checklist*

Extraction details form (adapted from Draper et al. 2019):	Reviewed by:	
	First author:	
	Year of publication:	
	Country:	
	Study aims:	
	Study design:	
	Description of the sample:	
	Population:	
	Setting:	
	Method to assess clinician emotional experience:	
	How is 'end of life' defined / measured:	
	Description of relevant findings, including the direction and significance of the reported relations:	
	CASP Section A: Are the results valid?	Was there a clear statement of the aims of the research?
		Comments:
	Is a qualitative methodology appropriate?	
	Comments:	
	Was the research design appropriate to address the aims of the research?	
	Comments:	
	Was the recruitment strategy appropriate to the aims of the research?	
	Comments:	
	Was the data collected in a way that addressed the research issue?	
	Comments:	
	Has the relationship between researcher and participants been adequately considered?	
	Comments:	
CASP Section B: What are the results?	Have ethical issues been taken into consideration?	
	Comments:	
	Was the data analysis sufficiently rigorous?	
	Comments:	
	Is there a clear statement of findings?	
	Comments:	
CASP Section C: Will the results help locally?	How Valuable is the research	
Total score (count of Yes' on CASP)		
Named emotions Log	Emotions experienced by Physican named in paper:	
Other comments:		

Figure C2

## COREQ

No.	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Inter viewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? (E.g. PhD, MD)
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? (e.g. personal goals, reasons for doing the research).
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? (e.g. Bias, assumptions, reasons and interests in the research topic)
Domain 2: Study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? (e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis).
Participant selection		
10.	Sampling	How were participants selected? (e.g. purposive, convenience, consecutive, snowball)
11.	Method of approach	How were participants approached? (e.g. face-to-face, telephone, mail, email)
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? (e.g. home, clinic, workplace)
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? (e.g. demographic data, date)
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? (e.g. participant number)
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

## Appendix D

**Table D1**

### Quality Review Outcomes

	Paper 1: Relational dialectics theory: Disentangling physician-perceived tensions of end-of-life communication	Paper 8: Death and End of Life: Perceptions Throughout the Career About Death, Palliative Care, and Educational Process	Paper 10: Junior Physicians' Views of How Their Undergraduate Clinical Electives in Palliative Care Influenced Their Current Practice of Medicine	Paper 13: Enabling first and second year Physicians to negotiate ethical challenges in end-of-life care: a qualitative study	Paper 15: Palliative care from the perspective of cancer physicians: a qualitative semi structured interviews study	Paper 16: Painting a Rational Picture During Highly Emotional End-of-Life Discussions: a Qualitative Study of Internal Medicine Trainees and Faculty	Paper 22: What are the barriers faced by medical oncologists in initiating discussion of palliative care? A qualitative study in Flanders, Belgium	Paper 25: Medical futility at the end of life: the perspectives of intensive care and palliative care clinicians	Paper 27: To speak, or not to speak – do clinicians speak about dying and death with geriatric patients at the end of life?	Paper 29: Swedish intensivists' experiences and attitudes regarding end-of-life decisions	Paper 32: Barriers to end-of-life discussions among haematologists : A qualitative study	Paper 35: Physicians' views on the usefulness and feasibility of identifying and disclosing patients' last phase of life: a focus group study	Paper 43: Moral distress in end-of-life decisions: A qualitative study of intensive care physicians	Paper 48: The lived experience of physicians dealing with patient death	Paper 49: "Treat them into the grave": cancer physicians' attitudes towards the use of high-cost cancer medicines at the end of life	Paper 50: Reasons Physicians provide futile treatment at the end of life: a qualitative study	Paper 51: On the emotional connection of medical specialists dealing with death and dying: a qualitative study of oncologists, surgeons, intensive care specialists and palliative medicine specialists	
Reviewed by:	JL	JL	JL	JL	JL	JL	JL	JL	JL	JL	JL	JL	JL	JL	JL	JL	JL	
First author:	Amati, R	Corradi M L	Crawford G B	Donnelly S.	Economos G	D El-Routy	Horlait M	Jox R J	Lenherr G	Nordenskjold Syrous A	Prod'homme C	Owusua C	St Ledger U	Whitehead P R	Wiersma M	Willmott L	Zambrano S C	
Year of publication:	2014	2020	2014	2021	2020	2020	2016	2012	2012	2020	2018	2021	2012	2012	2019	2016	2012	
Country:	Switzerland	Brasil	Australia	New Zealand	France	Canada	Belgium	Germany	Switzerland	Sweden	France	Netherlands	Belfast NI, UK	Canada	Australia	Australia	Australia	
CASP Section A: Are the results valid?	Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	
	Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
	Was the research design appropriate to address the aims of the research?	Can't Tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	Yes	
	Was the recruitment strategy appropriate to the aims of the research?	Yes	No	Yes	Yes	Yes	Can't Tell	Yes	No	Can't tell	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	
	Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes
	Has the relationship between researcher and participants been adequately considered?	No	Can't Tell	Yes	Can't Tell	Yes	Yes	Can't Tell	Yes	Yes	Yes	Can't tell	No	No	Yes	No	No	Yes
CASP Section B: What are the results?	Have ethical issues been taken into consideration?	No	Can't Tell	Yes	Can't Tell	Can't Tell	Can't Tell	Can't Tell	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	No	No	Yes	
	Was the data analysis sufficiently rigorous?	No	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	
CASP Section C: Will the results help locally?	Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
	How Valuable is the research	Yes, very	Yes, good	Yes, very	Yes, very	Yes, good	Yes, good	Yes, good	Yes, very	Yes, good	Yes, very	Yes, very	Yes, good	Yes, very	Yes, very	Yes, good	Yes, good	
Total score (count of Yes')	6/10	7/10	10/10	8/10	9/10	8/10	7/10	8/10	8/10	10/10	8/10	6/10	6/10	7/10	6/10	9/10	10/10	
Paper worth reviewing?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Paper withstand the COREQ gold standard?	No	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No	No	No	No	No	Yes	



## Appendix E

**Table E1**

*Systematic Review Results: Characteristics of the Seventeen Included Studies*

Authors (year, country, paper title)	Study aims	Design	Sample	Population, Setting	Method to assess clinician emotional experience	How 'end of life' is defined within the paper
Amati, R. and Hannawa, A. F. (2014, Switzerland) Relational dialectics theory: Disentangling physician-perceived tensions of end-of-life communication	RQ1: To what extent do physicians experience Baxter and Montgomery's (1996) dialectical tensions in end-of-life conversations with their patients and patients' families? RQ2: When exactly during end-of-life interactions with patients and their families do physicians commonly experience Baxter and Montgomery's (1996) dialectical tensions? RQ3: Are there any additional dialectical tensions physicians experience in end-of-life interactions with patients and their families?	Qualitative; semi-structured face-to-face and email interviews.	A convenience sample of 11 physicians who had experienced at least one end-of-life encounter with a patient. 8 = male 3 = female Average age was 48 years (range = 41–64, missing Ns = 3) and the average time of experience in their profession was 23 years (range = 15–38, missing Ns = 3).	Four different hospitals in a southern Swiss canton recruited through e-mail.	Interview question included: "Describe what it means to deal with a patient at the end of life." The transcripts were analysed thematically, using line-by-line coding. Description Baxter theory was presented, which introduced the emotional contradictions and prompted conversations - possibly limited results.	Subjective: participants were asked to define 'end of life'.
Corradi, M. L. G., Duim, E. and Rodrigues, C. I. S. (2020, Brazil) Death and End of Life: Perceptions Throughout the Career About Death, Palliative Care, and Educational Process	To evaluate the perception of attending physicians, medical residents, and undergraduate medical students about death and dying, the end-of-life (EOL), and palliative care (PC) during training and clinical practice, highlighting knowledge gaps, and the changes needed in medical school curricula.	Qualitative; semi-structured face-to-face interviews.	Cross-sectional study of 12 attending physicians, residents, and undergraduate medical students.	A single teaching hospital in Sao Paulo, Brazil. Randomly selected participants.	Capturing words through thematic analysis and included speech changes / speech markers in audio recordings.	Subjective: study alludes to the difficulties in defining death. Interns and residents defined death and dying within a broader spectrum, not limited to the absence of organic conditions intrinsic to life. For some, spiritual meaning was more

Authors (year, country, paper title)	Study aims	Design	Sample	Population, Setting	Method to assess clinician emotional experience	How 'end of life' is defined within the paper
						important than the biologic meaning of death.
Crawford, G. B. and Zambrano, S. C. (2015, Australia) Junior Physicians' views of how their undergraduate clinical electives in palliative care influenced their current practice of medicine	To explore how junior Physicians (Physicians in postgraduate training) retrospectively perceived the influence of their undergraduate palliative care attachments (clinical electives) on their current medical practice.	Qualitative; semi-structured face-to-face interviews.	From 2008 to 2013, eight students, who had participated in palliative care attachments at the University of Adelaide School of Medicine, were included in the study.	Junior Physicians from the University of Adelaide medical school cohort.	Thematic analysis by a psychologist with professional and research experience in palliative care and qualitative methodologies.	Questions asked about aspects of the palliative care attachments, the initial experiences with the death of a patient (as students and as junior physicians).
Donnelly, S. and Walker, S. (2021, New Zealand) Enabling first and second year Physicians to negotiate ethical challenges in end-of-life care: a qualitative study	To understand the unique ethical and professional challenges confronting first and second year Physicians in caring for people who are dying, and to learn what factors help or hinder them in managing these.	Qualitative; semi-structured face to face interviews.	Six first year and seven second year Physicians randomly recruited and were interviewed.	Fifty postgraduate Year 1 and 2 Physicians in the district health board area were invited to participate during their orientation week in December 2017. Auckland University Medical School (n=2); Otago University Medical School (n=11).	Interview question included: what sorts of ethical issues they encountered in caring for dying patients. No definition beyond that to describe what 'dying patients' meant to them or researcher.	No clear definition given by author, nor was it clear whether participants were asked to define what EOL means to them explicitly.
Economos, G., Bonneville-Levard, A., Djebari, I., Van Thuynes, K., Tricou, C., Perceau-Chambard, É. And Filbet, M. (2020, France) Palliative care from the perspective of cancer physicians: a qualitative semi structured interviews study	Exploration of Physicians' perceptions of palliative care and factors influencing reasons to refer to specialist palliative care.	Qualitative; semi-structured face-to-face interviews.	Forty-six physicians working in cancer care were invited and 18 interviews were conducted. Seven participants were women and 11 were men. 37.9 years old on average and had 13 years of professional experience. Physicians under 40 years old (n=13) had received undergraduate training in palliative care, and physicians over 40 (n=5) had never received any training in palliative care.	Two non-specific tertiary hospitals and one comprehensive cancer centre.	Questions asked participants to remember a specific experience of working with a dying patient, with prompts around 'regret'.	Subjective: questions included: 'What does palliative care mean to you?'

Authors (year, country, paper title)	Study aims	Design	Sample	Population, Setting	Method to assess clinician emotional experience	How 'end of life' is defined within the paper
El-Rouby, D., McNaughton, N. and Piquette, D. (2020 Canada) Painting a Rational Picture During Highly Emotional End-of-Life Discussions: a Qualitative Study of Internal Medicine Trainees and Faculty	To better understand how internal medicine attending physicians and trainees experience end-of-life discussions with patients and families during acute hospitalisations.	Qualitative; semi-structured face-to-face interviews using an interpretivist approach.	Participants included 9 physicians-in-training (7 residents and 2 clinical fellows) and 6 certified practitioners with a wide range of clinical experience (from first year of postgraduate training to more than 20 years of practice). Selected participants based on purposeful maximal variation and theoretical sampling strategies. Further sampling was based on our preliminary findings to pursue promising lines of inquiry (theoretical sampling).	Targeted representation from internal medicine physicians affiliated with the University of Toronto with various levels of clinical experience (junior residents, senior residents, or fellows, early and mid-career practicing physicians), over 5 different institutions, and different types of end-of-life discussions (with patient vs. with relatives, elective vs. urgent).	The initial interview guide was designed to elicit the following: 1. A recollection of a recent or memorable end-of-life discussion held by the participant, 2. Circumstances perceived to have affected the physicians' level of comfort and discomfort during past end-of-life discussions, 3. Characteristics of self-reported successful vs. unsuccessful end-of-life discussions, 4. Personal end-of-life views, values, and experiences.	Subjective: The question 'what is an effective end-of-life discussion?' offered opportunity for clarification for each participant, but their individual response similarities and differences weren't clearly outlined in the paper. Authors added direct questions after a pilot study about personal emotions experienced during routine and challenging end-of-life discussions because of the lack of spontaneous comments made on this topic by participants.
Horlait, M., Chambaere, K., Pardon, K., Deliens, L. and Van Belle, S. (2016, Belgium) What are the barriers faced by medical oncologists in initiating discussion of palliative care? A qualitative study in Flanders, Belgium	To identify the barriers experienced by Belgian medical oncologists when introducing palliative care to their patients with advanced cancer.	Qualitative; semi-structured face-to-face interviews.	Of the 82 who received letters of invitation, 15 certified medical oncologists responded and were included in the study, 11 male and 4 female. Their ages ranged from 37 to 70 years, and they varied in work experience from 8 to 44 years.	Online membership list of the Belgian Society of Medical Oncology (BSMO). Only Dutch-speaking members were taken into consideration.	The author reported that interviews were explorative with open-ended questions and were supported by a topic list compiled according to the results of an extensive literature review on the subject. The topic list was dynamic and was revised continuously during intermediate analysis. No clear questions on emotions elicited.	No clear definition given by author, nor was it clear whether participants were asked to define what EOL means to them explicitly.
Jox, R. J., Schaider, A., Marckmann, G. and Borasio, G. D. (2012, Germany) Medical futility at the end of life: the perspectives of intensive care and palliative care clinicians	Examining how physicians define futility, when they perceive life-sustaining treatment (LST) to be futile, how they communicate this situation and why LST is sometimes continued despite being recognised as futile.	Qualitative mixed-methods approach, firstly analysing protocols of ethics consultations and secondly semi-structured face-to-face interviews.	Analysed 17 ethics consultations over a 12-month period. For the interviews, used purposeful cluster and stratified sample of all physicians and nurses that were present at the ethics consultation meetings, interviewed 29 healthcare professionals, 17 from intensive care (12 physicians, 5 nurses) and 12 from palliative care (6 physicians, 6 nurses).	Drs and nurses in a large tertiary referral hospital in Germany. <i>Only views of drs were included in this systematic review.</i>	Semi-structured interview with a focus on futility - the word futility seemed to bring up emotions for people, as identified in paper.	Subjective: Interviewer asked for definition of futility from clinicians.

Authors (year, country, paper title)	Study aims	Design	Sample	Population, Setting	Method to assess clinician emotional experience	How 'end of life' is defined within the paper
<p>Lenherr, G., Meyer-Zehnder, B., Kressig, R. W. and Reiter-Theil, S. (2012, Switzerland)</p> <p>To speak, or not to speak -- do clinicians speak about dying and death with geriatric patients at the end of life?</p>	<p>Reviewed the willingness and difficulties of physicians and nurses to speak about dying and death with geriatric patients.</p>	<p>Qualitative; semi-structured face-to-face interviews.</p>	<p>Interviewed 35 clinicians (physicians = 31 and nurses = 4). 17 in an acute geriatric department of a university hospital and 18 in a geriatric community hospital.</p>	<p>Two clinical units located in Basel, Switzerland. Physicians and nurses were contacted by general email encouraging enrolment in the research. More experienced physicians and nurses were also specifically invited by heads of departments. <i>Only views of physicians were included in this systematic review.</i></p>	<p>Open-ended questions, and thematic analysis.</p>	<p>No clear definition given by author, nor was it clear whether participants were asked to define what EOL means to them explicitly.</p>
<p>Nordenskjöld Syrous, A., Ågård, A., Kock Redfors, M., Naredi, S. and Block, L. (2020, Sweden)</p> <p>Swedish intensivists' experiences and attitudes regarding end-of-life decisions</p>	<p>Firstly, identifying Swedish intensivists' experiences, beliefs, and attitudes regarding decision-making pertaining to EOL decisions. Secondly, identifying underlying factors that may contribute to variability in the decision-making process.</p>	<p>Qualitative; semi-structured face-to-face interviews.</p>	<p>Interviewed 19 intensivists (9 women and 10 men) from five different Swedish hospitals, with different ICU levels, from 1 February 2017 to 31 May 2017. All the respondents except two were educated in Scandinavia. The participants had a median age of 43 years (range 35-61) and had a median length of experience as intensivists of 8.5 (range 1-27) years.</p>	<p>The study was conducted in general intensive care units in two university hospitals, two midsize hospitals and one smaller county hospital in Sweden. The hospitals were selected to ensure a mix of hospitals of different sizes as well as different ICU levels and geographic locations. No specialised intensive care units (paediatric, neurological, or thoracic surgery) were included. Purposeful sample: at each of the selected hospitals, the ICU medical director was asked in an informative letter to find four consultants with different levels of experience and genders who were willing to participate in the study. Seventeen of the nineteen respondents did not know the interviewing researcher, two had only brief professional acquaintance.</p>	<p>Not clear within paper, beyond thematic analysis.</p>	<p>No clear definition given by author, nor was it clear whether participants were asked to define what EOL means to them explicitly.</p>

Authors (year, country, paper title)	Study aims	Design	Sample	Population, Setting	Method to assess clinician emotional experience	How 'end of life' is defined within the paper
Owusuaa, C., van Beelen, I., van der Heide, A. and van der Rijt, C. C. D. (2021, Netherlands) Physicians' views on the usefulness and feasibility of identifying and disclosing patients' last phase of life: a focus group study	Exploring physicians' views on identifying and disclosing the last phase of life of patients with different illness trajectories.	Mixed methods; two semi-structured focus groups, following a questionnaire.	Fifteen medical specialists and general practitioners participated. Fifteen of the 16 physicians (10 female and 5 male) who completed the questionnaire participated in one of the two focus group meetings: 7 oncologists, 3 GPs, 2 specialists in elderly care, 2 pulmonologists and 1 pain specialist. All participants worked with either cancer or COPD patients.	Recruited from eight hospitals using the snowball method through multidisciplinary oncology boards, aiming to recruit one pulmonologist from each hospital, and four specialists in elderly care or general practice.	Not clear within paper, beyond thematic analysis. Questions from focus group were not published.	EOL was defined by author as expected death within 1 year.
Prod'homme, C., Jacquemin, D., Touzet, L., Aubry, R., Daneault, S. and Knoops, L. (2018, France) Barriers to end-of-life discussions among haematologists: A qualitative study	To determine haematologists' barriers to end-of-life discussions when potentially fatal haematological malignancies recur.	Qualitative; semi-structured face-to-face interviews, using grounded theory to synthesise data.	Haematologists (n=10) from four haematology units. The mean age of the haematology oncologists was $43.5 \pm 7$ years; four were men (40%) and four were Belgian. Six worked in a university hospital. Four had complementary training in health ethics and one in palliative care. The participants had been practicing haematology for $13.5 \pm 7$ years. Interviews lasted 61 min on average (range 31–114 min). Haematologists were excluded from the study if they did not speak French, knew the investigator, and knew the goal of the interview.	Haematology units in healthcare institutions located in northern France and Belgium: two private university hospitals (Lille, France and Louvain, Belgium) and two public general hospitals (Roubaix and Arras, France).	In-depth and semi-structured interviews explored the participants' experiences and the meanings they attributed to them.	Author clarified that for this study EOL is referring to when potentially fatal haematological malignancies recur.
St Ledger, U., Reid, J., Begley, A., Dodek, P., McAuley, D. F., Prior, L. and Blackwood, B. (2021, Northern Ireland) Moral distress in end-of-life decisions: A qualitative study of intensive care physicians	Explores triggers for moral distress, and constraints preventing physicians from doing 'the right thing' and ensuing consequences in making decisions for patients approaching end-of-life in intensive care.	Qualitative; semi-structured face-to-face interviews, theoretically orientated around 'moral distress'.	Eighteen senior and junior physicians involved in 21 patient case studies were interviewed. Sample working predominantly in ICU were purposively sampled. Interviews lasted between 40 and 60 min.	Tertiary referral 25 bed intensive care unit which operated on a closed management model in a hospital in Northern Ireland in the United Kingdom.	No interview schedule and therefore it was unclear how the authors got this level of disclosure.	Author asked clinicians interviewed to draw upon patient case studies of decisions about non-escalation and/or withdrawal of life support.

Authors (year, country, paper title)	Study aims	Design	Sample	Population, Setting	Method to assess clinician emotional experience	How 'end of life' is defined within the paper
Whitehead, P. R. (2012, Canada) The lived experience of physicians dealing with patient death	To explore physicians' experiences of dealing with patient death in order to understand how such experiences affect them and their communication with patients.	Qualitative; semi-structured face-to-face interviews.	10 senior physicians (5 male, 5 female, all Caucasian) from several specialty areas at a large, tertiary care hospital. All participants had a minimum of 3 years' work experience and self-identified as being exposed to multiple patient deaths. Three came from palliative care, two from emergency, two from hospital transplant teams, two from family practice and one from intensive care. The physicians ranged in age from 35 to 60 (average 48) and had from 6 years to over 20 years of experience (average 16.5).	A large, tertiary care hospital in Vancouver, Canada. Participants represented a convenience sample identified through informal work contacts and then contacted with a formal letter of invitation. Interest in participating in this study was in part due to Kuhl's earlier research that identified 'iatrogenic suffering'. This previous research was known to most of the participants, and the letter of invitation identified that the current study was a follow-up to that research.	Asked an initial question about a particularly memorable patient death.	Subjective: Interviewer focused on reflections on death - retrospective.
Wiersma, M., Ghinea, N., Kerridge, I. and Lipworth, W. (2019, Australia) 'Treat them into the grave': cancer physicians' attitudes towards the use of high-cost cancer medicines at the end of life	Explored the factors perceived by cancer physicians to be driving the use of high-cost cancer medicines at the end-of-life.	Qualitative; semi-structured face-to-face interviews.	16 Australian oncologists and haematologists. Many participants held multiple roles – for example, clinical positions, academic affiliations and/or senior government advisory roles (not specified).	Recruited for interviews via convenience sampling, snowball sampling and unsolicited emails to experts with relevant professional backgrounds. These sampling strategies were used in order to achieve maximum variation.	Interview questions focused on the competing values about access cancer medicines and the different factors that underpin decisions.	No clear definition given by author, nor was it clear whether participants were asked to define what EOL means to them explicitly.
Willmott, L., White, B., Gallois, C., Parker, M., Graves, N., Winch, S., Callaway, L. K., Shepherd, N. and Close, E. (2016, Australia) Reasons Physicians provide futile treatment at the end of life: a qualitative study	Investigation into why Physicians believe that treatment they consider to be futile is sometimes provided at the end of a patient's life.		96 Physicians from emergency, intensive care, palliative care, oncology, renal medicine, internal medicine, respiratory medicine, surgery, cardiology, geriatric medicine, and medical administration departments. Many Physicians were consultants (87), with nine registrars interviewed. Their ages ranged from 30 to 72, with a mean age of 49 years. The average amount of time working as a Physician was 22 years (range 5–49 years).	Participants were recruited using purposive maximum variation sampling from three large tertiary public hospitals in Brisbane, Australia.	Not clear within paper, beyond thematic analysis.	No clear definition given by author, nor was it clear whether participants were asked to define what EOL means to them explicitly.

Authors (year, country, paper title)	Study aims	Design	Sample	Population, Setting	Method to assess clinician emotional experience	How 'end of life' is defined within the paper
<p>Zambrano, S. C., Chur-Hansen, A. and Crawford, G. B. (2012, Australia) On the emotional connection of medical specialists dealing with death and dying: a qualitative study of oncologists, surgeons, intensive care specialists and palliative medicine specialists</p>	<p>Explored the experiences and coping mechanisms of medical specialists from the specialties of intensive care, surgery, oncology, and palliative care, when dealing with death and dying and their emotional connection with dying patients in the context of a life-threatening illness.</p>	<p>Qualitative; semi-structured face-to-face interviews.</p>	<p>11 oncologists, nine surgeons, six intensive care specialists and seven palliative medicine specialists. Years of medical practice ranged from 6 to 45 years, with an average of 25 years. Ten participants were women and 23 were men. Twenty-four were working full-time.</p>	<p>A total of 52 specialists were contacted. Thirty-seven (71%) agreed to participate in the study but only 33 were interviewed due to data saturation. Purposeful sampling was used to allow the selection of targeted informants. Participants were selected according to their specialty, gender, age range and years of practice. Eligible participants were practicing in the city of Adelaide at the time of the interview.</p>	<p>Interview questions were guided by the interviewee's responses. Interviews were also complemented by previous participants' responses, employing the process of constant comparison. Subsequent thematic analysis.</p>	<p>No clear definition given by author, nor was it clear whether participants were asked to define what EOL means to them explicitly.</p>

## Appendix F

### Systematic Review – Grouping Emotions

The list of emotions identified in the systematic review were grouped against pre-existing theories of emotions by Robinson (2008) and Sacharin, Schlegel & Scherer (2012) as a platform for building themes.

Table F1 derives from a framework conceptualised in Robinson (2008) which considered thirteen theories on emotion and relative categories as developed by Ortony and Turner (1990). It was used to categorise all emotions identified across all reviewed papers and supported the author in the development of themes. According to this framework, many of the emotions captured in the studies related to a doctor's self-appraisal, in that they either showed pride and confidence in their skills, or a sense of failure embarrassment or remorse. This was followed by event-based emotions, namely relief or frustration or disappointment about the outcome of the event. Future appraisal-based emotions were the third most frequent identified, namely fear and apprehension.

Figure F2 is a diagram based on the work by Sacharin, Schlegel & Scherer (2012), to understand how emotions are linked and distinct, and adapted by Scherer, Shuman, Fontaine et al. (2013) to include the impact of power on how emotions are experienced. Emotions that were identified more than 4 times across all the papers were mapped against this diagram. The aim of grouping emotions in this way was to look more generally at relationships between emotions, not otherwise identified by the method in Table F1. Using this method, the author identified that most emotions were positioned between low power



and control and a sense of unpleasantness. Only acceptance, identified 4 times across all papers, was shown to be linked with moderate levels of power and control and pleasantness.

**Table F1**

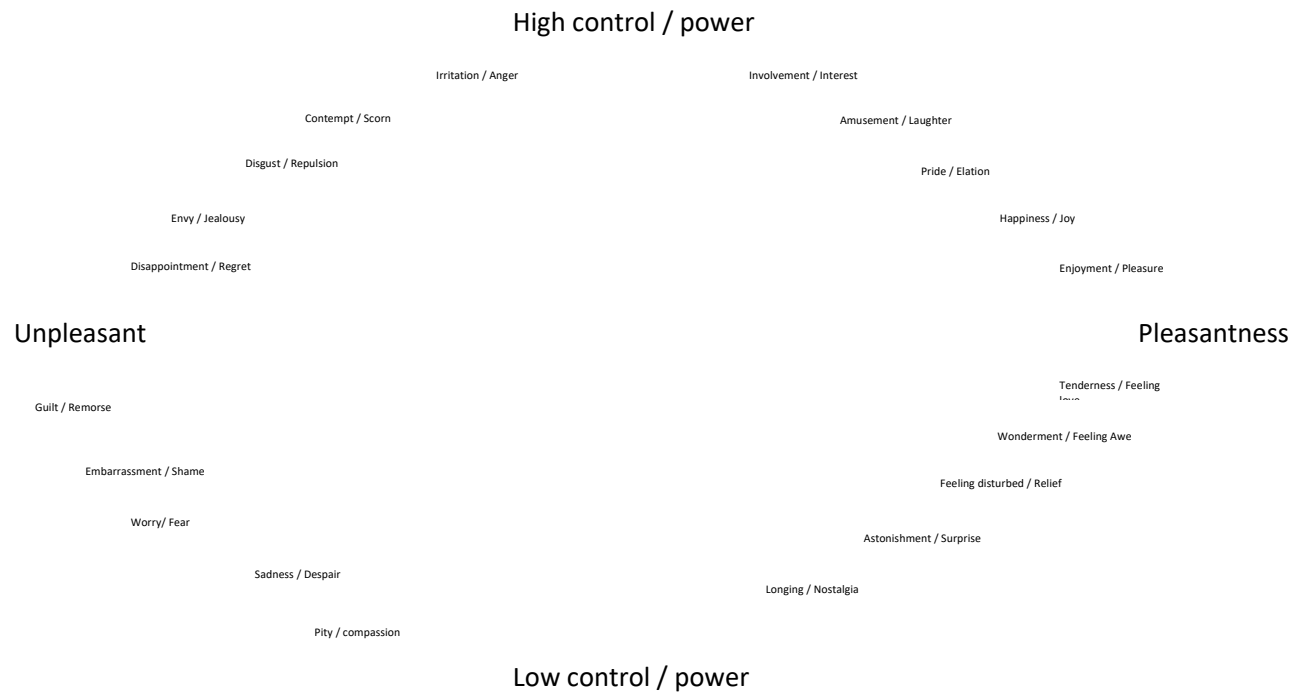
*Named Emotions Grouped on the Categories Organised by Robinson (2008)*

Emotions identified (number of times identified within context, and %age of all emotions identified)						
Kind of emotion	Positive emotions examples	Negative emotions examples	Positive emotions	Sum (%) of positive emotions	Negative emotions	Sum (%) of negative emotions
EMOTIONS RELATED TO OBJECT PROPERTIES	Interest, curiosity	Alarm, panic	Curious (1, 0.27%) Enjoyment (1, 0.27%) Focused (1, 0.27%) Passion (1, 0.27%)	4 (1.08%)	Identification with mortality (7, 1.92%), Concern (3, 0.82%) Abrupt (1, 0.27%) Shock [at so few burnout cases] (1, 0.27%) Oh my god (1, 0.27%) Overwhelming (1, 0.27%) Pressure (1, 0.27%) Unprepared (1, 0.27%) Whirlwind (1, 0.27%)	(17, 4.63%)
	Attraction, desire, admiration.	Aversion, disgust, revulsion.	Appreciated (2, 0.55%)	2 (0.55%)	Reluctant / reluctance (3, 0.82%) Uncomfortable (5, 1.37%) Repressing (2, 0.55%) Intolerable (1, 0.27%) Separation (1, 0.27%) Denial (1, 0.27%)	13 (3.55%)
	Surprise, amusement.	Indifference, familiarity, habituation.	Easy (1, 0.27%)	1 (0.27%)	Personal /Personal identification (12, 3.30%), Compassion fatigue (1, 0.27%) Disconnect (1, 0.27%) Emotionally hardening (1, 0.27%) Inevitable (1, 0.27%) Machine (1, 0.27%) Thicker skin (1, 0.27%) Unexpected (1, 0.27%) Uninvolved (1, 0.27%)	20 (5.46%)
FUTURE APPRAISAL EMOTIONS	Hope	Fear	Breakthrough (2, 0.55%) Balanced (1, 0.27%)	3 (0.82%)	Fear of... (13, 3.57%), Apprehension / apprehensive (3, 0.82%) Fear of criticism (3, 0.82%) Worry (2, 0.55%) Gut feeling (2, 0.55%) Scared, scary (2, 0.55%) Vulnerable (2, 0.55%) Final / Irrevocable (1, 0.27%) Frightened (1, 0.27%) Horrendous (1, 0.27%) Stigma (1, 0.27%) Terror (1, 0.27%) Vivid (1, 0.27%)	33 (9.03%)
EVENT RELATED EMOTIONS	Gratitude, thankfulness.	Anger, rage.	Accepting (4, 1.10%) Valued (1, 0.27%)	5 (1.37%)	Grating (1, 0.27%) Inhuman (1, 0.27%) Unequal (1, 0.27%) Anger (1, 0.27%) Disregard (1, 0.27%)	5 (1.35%)
	Joy, elation, triumph, jubilation.	Sorrow, grief.	Glad (2, 0.55%) Good (2, 0.55%)	4 (1.08%)	Deeply personal (12, 3.30%), Distressed (4, 1.1%) Sad / sadness (3, 0.82%) Cathartic (1, 0.27%) Depressing (1, 0.27%) Futile (1, 0.27%) Grief (1, 0.27%) Grim (1, 0.27%) Hit home (1, 0.27%) Intense (1, 0.27%) Stays with me (1, 0.27%) Brutal (1, 0.27%) Tragedy (1, 0.27%)	29 (7.92%)
	Relief	Frustration, disappointment	Don't like (2, 0.55%) Not a failure (2, 0.55%) Prepared (2, 0.55%) Clean (1, 0.27%) Relieved (1, 0.27%)	8 (2.19%)	Struggle / Struggled / Struggles (8, 2.20%), Exhausting / exhaustion / tired (5, 1.37%) Demanding (3, 0.82%) Frustrating (3, 0.82%) Challenging (2, 0.55%) Not easy (2, 0.55%) Defeat (1, 0.27%) Disappointment (1, 0.27%) Dissatisfaction (1, 0.27%) Hampered (1, 0.27%) Hopeless / hopelessness (1, 0.27%) Impossible (1, 0.27%) Left (1, 0.27%) Morally Troubling (1, 0.27%) Troubling (1, 0.27%) Useless (1, 0.27%) Unfulfilled (1, 0.27%)	34 (9.3%)

Emotions identified (number of times identified within context, and %age of all emotions identified)						
Kind of emotion	Positive emotions examples	Negative emotions examples	Positive emotions	Sum (%) of positive emotions	Negative emotions	Sum (%) of negative emotions
SELF APPRAISAL EMOTIONS	Pride in achievement, self-confidence, sociability	Embarrassment, shame guilt, remorse.	Comfortable (2, 0.55%) Confident (2, 0.55%) Courage (1, 0.27%) Peaceful (1, 0.27%) Rewarding (1, 0.27%) Satisfaction (1, 0.27%) Sense of control (1, 0.27%) Sense of self confidence (1, 0.27%) Shame (1, 0.27%) Useful (1, 0.27%)	12 (3.26%)	Difficult (19, 5.22%), Hard (15, 4.12%), Fail/failing/failure (14, 3.85%), Sense of responsibility (5, 1.37%) Uncertain / Uncertainty (5, 1.37%) Worry about competence (4, 1.10%) Sense of expectation (4, 1.1%) Stress/stressful (4, 1.1%) Burden / burdensome (3, 0.82%) Loss [of credibility / trust] (2, 0.55%) Unresolved (2, 0.55%) Blame (1, 0.27%) Conviction (1, 0.27%) Exposed (1, 0.27%) Impotence (1, 0.27%) Inadequate (1, 0.27%) Decision regret (1, 0.27%) Weighs heavily (1, 0.27%) Comparison (1, 0.27%) Laden (1, 0.27%)	86 (23.58%)
SOCIAL EMOTIONS	Generosity	Avarice, greed, miserliness, envy, jealousy.		0 (0%)		0 (0%)
	Sympathy	Cruelty	Empathise /empathy (1, 0.27%)	1 (0.27%)	Not wanting to... [action on patient / patient protecting] (8, 2.20%), Emotionally over-involved (6, 1.65%) Distant / Distance (4, 1.1%) Feeling others state (4, 1.1%) Attached (3, 0.82%) Emotive (3, 0.82%) Not empowered 1, 0.27%)	29 (7.92%)
CATHECTED EMOTIONS (to invest emotional energy)	Love	Hate				
EXPERIENCED EMOTION NOT SPECIFICALLY DESCRIBED			Emotion /emotionally/emotional [un-named otherwise] (57, 15.66%)			

## Figure F2

*Key Words Grouped on to the Geneva Emotion Wheel (Sacharin et al., 2012; adapted)*





## Appendix G

### Example Process of Analysis

Extract taken from systematic review theme 3.4.1.2 Knowing and accepting the limits of curative medicine.

*'...there was evidence that power played a role in acceptance – the wrestle of power between illness and physician, the power balance between medical professionals in a team, and the power dynamics between patient and physician.'*

An example of how this interpretative statement was drawn from analysis of a selection of papers:

#### Corradi, Duim, & Rodrigues, 2020

'...all reported difficulties in ... expressing negative feelings such as strangeness, discomfort, sadness and pain, anguish, impotence, frustration, powerlessness, insecurity, and, sometimes, apathy...'

' [Participants] appeared insecure when talking about this subject; their responses evinced a lack of interest...'

'Speech markers [described] obvious surprise, choking up, and long pauses ... a stark contrast to [what had been said].'  
'...focus on preserving life instead of providing quality care... illness-oriented, disregarding the individuality of the human being.'

[Quote] "'People often go into medicine with a beautiful dream that nobody dies, that you will take care of everyone and everyone will thank you''

#### Donnelly & Walker, 2021

'[Physicians] can find the death of a patient to be an emotional and sometimes disturbing experience and are likely to interpret a death as a failure related to their own incompetence.'

'...we asked for an opinion, [the patient] expressed it, and then we just decided we weren't gonna do it anyway.'

'' The way I was treated, the way [senior consultants from specific specialities] treated their patients, their bedside manner, everything about it was grating, the way they viewed elderly people particularly, I just found sickening. They really had the mentality of, 'oh well they're close to the end of their lives so it doesn't really matter now''.

#### Crawford & Zambrano, 2015

'' When I was doing the surgical rotation... the surgeons, didn't want to stop the treatments, to the point that ... I had to turn around and ask, "Do you think we should be contacting palliative care?" We ended up doing that eventually, when I made it seem like it was their idea.''

#### St Ledger et al., 2021

'...pressure from other clinicians and relatives to make premature decisions...'

''' There can be a self-fulfilling prophecy that the patient will not survive... so, until the end-of-life decision is made, palliative care should not be commenced [in case it prevents patient and clinician hope].'''

'Buying time...'

'...transition to palliative care ... was "intolerable"'.  
'

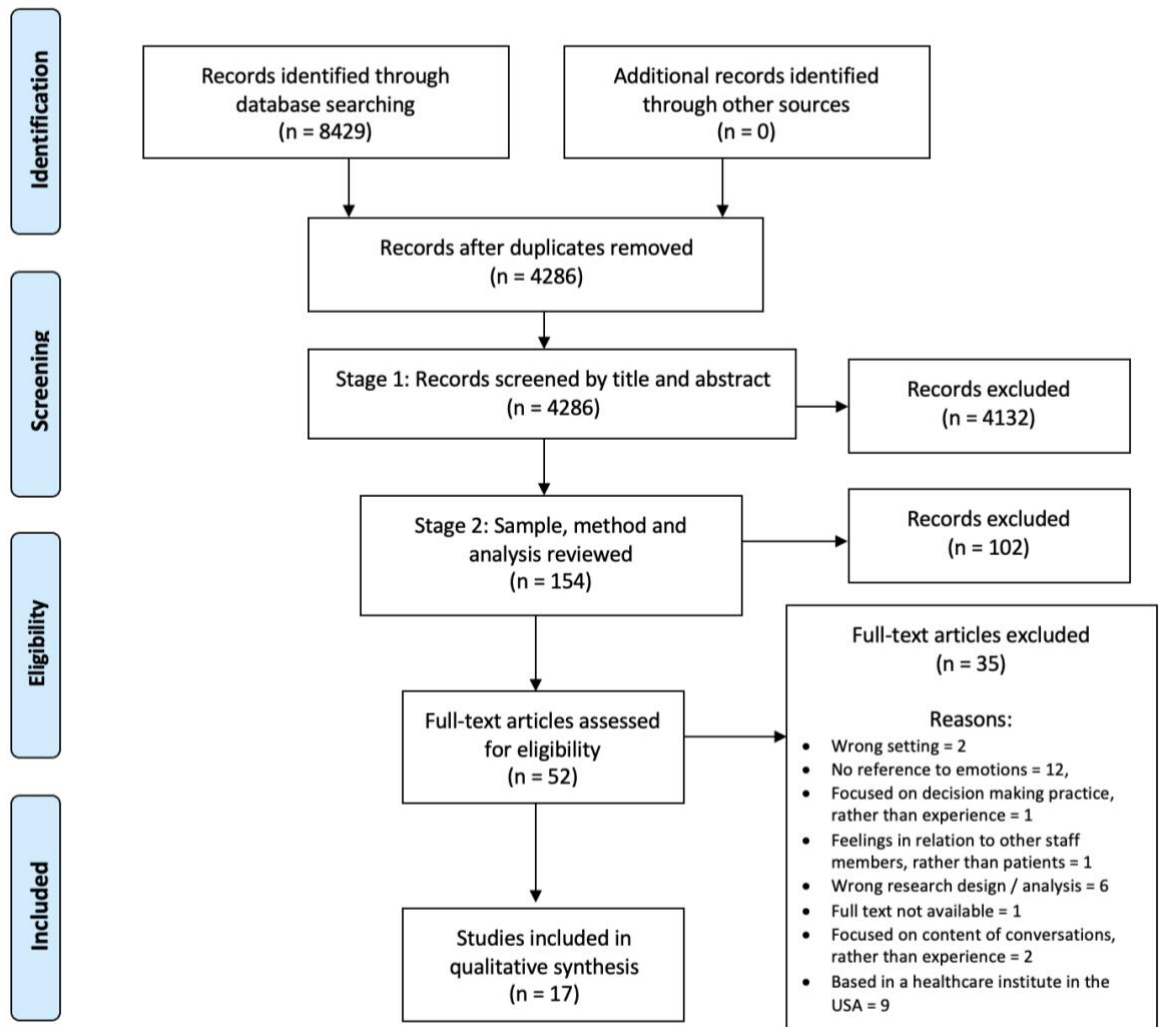
Jox et al., 2012

''' Often times it is the doctors that are unable to say: 'ok, let's stop' .... I don't know whether that has something to do with their ego that they think: 'I do not want to lose him now.''''

## Appendix H

Figure H1

Prisma Flow Diagram



Note. Included and excluded papers based on the Prisma Flow diagram (Eicke, 2017)



## Appendix I

### Research Committee Approval Letter



John Latham  
Clinical Psychology Trainee  
Doctorate in Clinical Psychology Programme  
University of Liverpool  
L69 3GB

**D.Clin.Psychology Programme**  
Division of Clinical Psychology  
Whelan Building, Quadrangle  
Brownlow Hill  
LIVERPOOL  
L69 3GB

Tel: 0151 794 5530/5534/5877  
Fax: 0151 794 5537  
[www.liv.ac.uk/dclipsychol](http://www.liv.ac.uk/dclipsychol)

27 August 2020

**RE:** Are a clinician's personal fears of failure related to confidence in and comfort with the delivery of end-of-life care in the workplace?

**Trainee:** John Latham

**Supervisors:** Sarah Butchard, Luna Centifanti and Stephen Mason

Dear Johnny,

Thank you for your notification of amendment to your proposal submitted to the Chair of the D.Clin.Psychol. Research Review Committee.

I can now confirm that your proposal (*version number 12, dated 28<sup>th</sup> July 2020*) meets the requirements of the committee and have been approved by the Committee Chair.

Please take this Chairs Action decision as **final** approval from the committee.

You may now progress to the next stages of your research.

I wish you well with your research project.

Dr Ross White  
Vice Chair D.Clin.Psychol. Research Review Committee

A member of the  
Russell Group

Dr Laura Golding  
Programme Director  
[lgolding@liv.ac.uk](mailto:lgolding@liv.ac.uk)

Dr Gundi Kiemle  
Academic Director  
[gkiemle@liv.ac.uk](mailto:gkiemle@liv.ac.uk)

Dr Jim Williams  
Joint Clinical Director  
[j.williams@liv.ac.uk](mailto:j.williams@liv.ac.uk)

Dr Beth Greenhill  
Joint Clinical Director  
[bethr@liv.ac.uk](mailto:bethr@liv.ac.uk)

Dr Ross White  
Research Director  
[rwhite@liv.ac.uk](mailto:rwhite@liv.ac.uk)

Mrs Sue Knight  
Programme Co-ordinator  
[sknight@liv.ac.uk](mailto:sknight@liv.ac.uk)

## Appendix J

### Sponsorship Review Panel Approval Letter

Dr Sarah Butchard  
School of Psychology,  
University of Liverpool  
Eleanor Rathbone Building,  
Bedford Street South,  
Liverpool,  
L69 7ZA



**Dr Neil French**  
**Head of Clinical Operations**

University of Liverpool  
Research Support Office  
2nd Floor Block D Waterhouse  
Building  
3 Brownlow Street  
Liverpool  
L69 3GL

Tel: 0151 794 8739  
Email: [sponsor@liv.ac.uk](mailto:sponsor@liv.ac.uk)

05 November 2020

Sponsor Ref: UoL001588

#### Re: Sponsorship Approval

**To investigate whether a clinician's personal fears of failure related to confidence in and comfort with the delivery of end-of-life care, using a combination of standardised measures**

Dear Dr Butchard

After consideration at the SPARK Non Interventional Sponsorship Sub Committee on 29<sup>th</sup> September 2020 I am pleased to confirm that the University of Liverpool is prepared to act as Sponsor under the UK Policy Framework for Health and Social Care Research (v3.2 10th October 2017) for the above study.

The following documents have been received by the Joint Research Office

Document title	Version	Date
Protocol	3.2	03/11/20

**Please note this letter does NOT allow you to commence recruitment to your study.**

A notification of Sponsor Permission to Proceed will be issued when governance and regulatory requirements have been met. Please see Appendix 1 to this letter for a list of the documents required.

If you have not already applied for regulatory approvals through IRAS you may now do so at <https://www.myresearchproject.org.uk/Home.aspx> (see SOP013).

In order to meet the requirements of the UK Policy Framework for Health and Social Care Research (v3.2 10th October 2017), the University requires you to agree to the following Chief Investigator responsibilities. Please see SOP006 for further details of delegated responsibilities;

TEM012 JRO UoL Sponsor Approval template  
Version 7.02 Date 21/02/2018



Dr Sarah Butchard  
 Institute of Population Health  
 University of Liverpool,  
 Waterhouse Building, Block B,  
 Brownlow Street,  
 Liverpool,  
 L69 3GF

**Dr Neil French**  
**Head of Clinical Operations**

Clinical Directorate  
 4th Floor Thompson Yates Building  
 Faculty of Health and Life Sciences  
 University of Liverpool  
 Liverpool L69 3GB

Tel: 0151 794 5852  
 Email: [sponsor@liverpool.ac.uk](mailto:sponsor@liverpool.ac.uk)

13 April 2021

Sponsor Ref: UoL001588

**Re: Sponsor Permission to Proceed notification**

**To investigate whether a clinician's personal fears of failure related to confidence in and comfort with the delivery of end-of-life care, using a combination of standardised measures**

Dear Dr Butchard,

All necessary documentation and regulatory approvals have now been received by the University of Liverpool Research Support Office in its capacity as Sponsor, and we are satisfied that all Clinical Research Governance requirements have been met. You may now proceed with any study specific procedures to open the study.

The following REC Approved documents have been received by the Research Support Office. Only these documents can be used in the recruitment of participants. If any amendments are required please contact the Research Support Office.

Document title	Version	Date
Participant Information Sheet	2.3	30 March 2021
Consent Form	2.3	30 March 2021
Protocol	3.4	March 2021

Please note, under the terms of your Sponsorship you must;

1. Gain NHS Confirmation of Capacity and Capability from each participating site before recruitment begins at that site;
2. Ensure all required contracts are fully executed before recruitment begins at any site;

TEM013 UoL Permission to Proceed notification  
 Version 5.00 Date 24/08/2016

## Appendix K

### NHS HRA Review Board Approval Letter



Ymchwil Iechyd  
a Gofal Cymru  
Health and Care  
Research Wales



Dr Sarah Butchard  
Mossley Hill Hospital  
Park Ave  
Liverpool  
L18 8BU

Email: [approvals@hra.nhs.uk](mailto:approvals@hra.nhs.uk)  
[HCRW.approvals@wales.nhs.uk](mailto:HCRW.approvals@wales.nhs.uk)

18 December 2020

Dear Dr Butchard

**HRA and Health and Care  
Research Wales (HCRW)  
Approval Letter**

**Study title:** Are a clinician's personal fears of failure related to confidence in and comfort with the delivery of end-of-life care in the workplace?

**IRAS project ID:** 289310

**Protocol number:** UoL001588

**REC reference:** 20/HRA/5930

**Sponsor:** University of Liverpool

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

## Appendix L

### Research Budget

#### Research Budget

**Project title:** Is confidence in and comfortableness with the delivery of end-of-life care related to a clinician's Fear of Failure in the workplace.

**Trainee:** John Latham

**Email:** John.Latham@liverpool.ac.uk

**Date:** 07.05.2020

Primary Supervisor: Sarah Butchard

Secondary Supervisors: Luna Centifanti

External Supervisor: Stephen Mason

#### Details of Photocopying/Printing

Photocopying @ <b>4p</b> per sheet 200 information sheets @ 10p per page x 2 pages	£40.00
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#### Description of Psychological Tests/Measures

Licenced to university or no cost	£N/A
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#### Description of Computer Software/Licenses

Qualtrics	£N/A
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#### Participant Cost

Participants will not be paid to take part in the research, but instead will be offered the opportunity to donate £5 to charity per completion	£450
Some budget would like to be allocated to provide tea, coffee and cakes when visiting wards to recruit participants.	
Tea Bags pack of 80 = £2.00, Coffee 200g = £4.00 Sugar 1kg = 65p, Milk 10 @ 58p = £5.80 Biscuits/cakes x4 packs @ £1.00 = £4.00	£16.45
ExE involvement (9 hours @ £14.59)	£131.31

#### Miscellaneous

Dissemination of research findings:	
a. Conference attendance	£300
b. Printed information for clinicians (200 information sheets @ 10p per page x 2 pages)	£40

N/A	
<b>Grand Total of Estimated Costs</b>	<b>£977.76</b>

## Appendix M

### Gpower Calculated Sample Size

Figure M1

#### Planned Analysis GPower Output

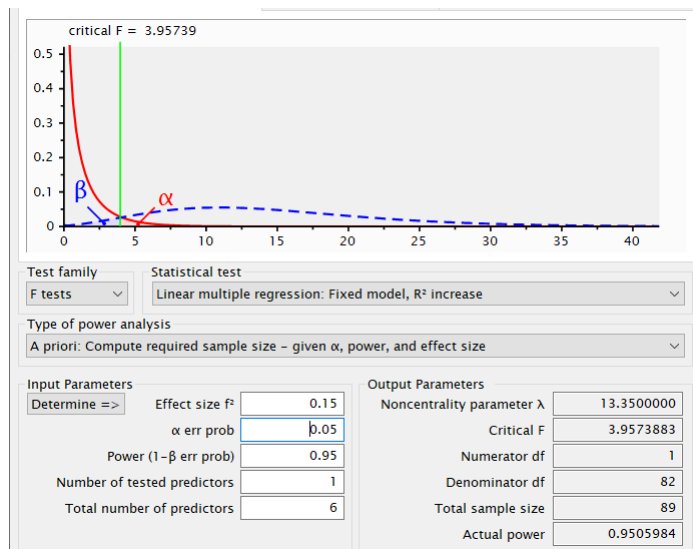
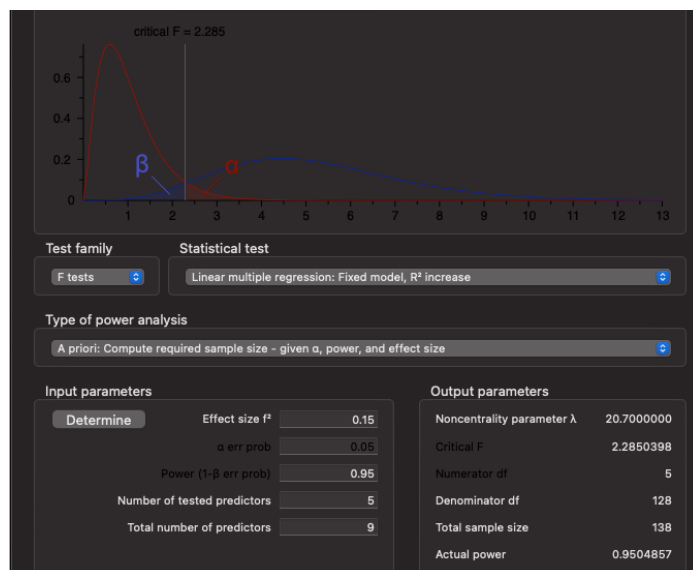


Figure M2

#### Exploratory Analysis GPower Output



## Appendix N

### Freedom Of Information Request Data

Figure N1

#### Liverpool Hospitals NHS FT Trust FOI Request Data

In-hospital Deaths at Aintree & Royal/Broadgreen  
University Hospital  
December 2019 to November 2020

Hospital	Ward Name / number	Ward Specialty	Number of Deaths
Royal & BG	AMAU	Geriatric Medicine	106
Aintree	Ward 08	Cardiology	115
Aintree	Critical care A	Critical care	103
Aintree	Ward 20 Acute Medicine	ENDOCRINOLOGY AND DIABETES	131
Aintree	Ward 32	Geriatric Medicine	106
Aintree	Ward 23	Respiratory Medicine	129
Royal & BG	ITU	Critical care medicine	85
Royal & BG	AMAU	General Medicine	73
Royal & BG	AMAU	Palliative Medicine	86
Royal & BG	AMAU	Respiratory Medicine	94
Aintree	Ward 21	DIABETES	77
Aintree	Ward 11	GASTROENTEROLOGY	73
Aintree	Acute Medicine Unit	General internal Medicine	90
Aintree	Ward 25 medical	General internal Medicine	90
Aintree	Ward 33	Geriatric Medicine	80
Aintree	Ward 22 Thoracic	Respiratory Medicine	78
Royal & BG	Ward 30	Geriatric Medicine	68
Royal & BG	AMAU	Infectious Diseases	58
Royal & BG	AMAU	GASTROENTEROLOGY	52
Royal & BG	AMAU	Endocrinology	53
Royal & BG	ACU - Acute Cardiology Unit	Cardiology	17
Royal & BG	AMAU	Clinical Pharmacology	17
Royal & BG	3x	Critical care medicine	13
Royal & BG	8HDU	Critical care medicine	11
Royal & BG	amau	Critical care medicine	27
Royal & BG	Esau	Critical care medicine	11
Royal & BG	AMAU	diabetic medicine	12
Royal & BG	7B	diabetic medicine	22
Royal & BG	5x	GASTROENTEROLOGY	12
Royal & BG	5Y	GASTROENTEROLOGY	20
Royal & BG	2B	Geriatric Medicine	24
Royal & BG	AIFU	Geriatric Medicine	20
Royal & BG	GPAU	Geriatric Medicine	14
Royal & BG	3x	Infectious Diseases	14
Royal & BG	3Y	Infectious Diseases	10
Royal & BG	AMAU	Nephrology	17
Royal & BG	APCU	Palliative Medicine	29
Royal & BG	ESAU	Palliative Medicine	15
Royal & BG	GPAU	Palliative Medicine	10
Royal & BG	GY	Respiratory Medicine	29
Royal & BG	AIFU	Respiratory Medicine	12
Royal & BG	GPAU	Respiratory Medicine	10
Royal & BG	8A	Vascular Surgery	12
Aintree	Ward 17A Urology	General internal Medicine	13
Aintree	Ward 19 Integrated Medicine	General internal Medicine	11
Aintree	Ward 21	General internal Medicine	17
Aintree	Major Trauma Ward	General Surgery	19
Aintree	Ward 04 General Surgery	General surgery	14
Aintree	Ventilation Inpatient Centre (ECC)	Respiratory Medicine	14
Aintree	Ward 24 Thoracic	Respiratory Medicine	18
Aintree	Ward 25 Medical	Respiratory Medicine	11
Aintree	Ward 01 Orthopaedics	Trauma and Orthopaedics	22
Aintree	Ward 03 Orthopaedics	Trauma and Orthopaedics	10
Aintree	Ward 16A	Trauma and Orthopaedics	11

Key	
Over 100 deaths	Yellow
70-100 deaths	Blue
50-70 deaths	Purple
30-50 deaths	green
10-30 deaths	Pink
Under 10 deaths	white

## Figure N2

## York &amp; Scarborough Hospitals NHS FT Trust FOI Request Data

Number of Deaths at York Teaching Hospital NHS Foundation Trust by Ward

01-Jan-2020 to 31-Dec-2020

Important Note [added by trust]: Ward Specialty is based on normal activity, wards may have been re-purposed as Covid-19 wards for a certain period of time in the last 12 months

Hospital	Discharging Ward	Ward Name	Ward Specialty	Number of Deaths	Impact of covid
YORK HOSPITAL	IC	Intensive Care Unit	Critical Care	147	
SCARBOROUGH HOSPITAL	BEE	Beech	Respiratory Medicine - Thoracic	100	Unchanged
YORK HOSPITAL	23	Twenty Three	Geriatric Medicine	95	Mixed wards - was elderly so was high - but not anymore
YORK HOSPITAL	28	Twenty Eight	Geriatric Medicine	90	Surgical ward - few
YORK HOSPITAL	35	Thirty Five	Geriatric Medicine	84	Covid ward
SCARBOROUGH HOSPITAL	OAK	Oak	Geriatric Medicine	78	Unchanged
YORK HOSPITAL	34	Thirty Four	Respiratory Medicine - Thoracic	77	Unchanged
YORK HOSPITAL	29	Twenty Nine	Trauma And Orthopaedic Surgery	74	Covid ward
SCARBOROUGH HOSPITAL	LIL	Lilac Ward	Acute Internal Medicine	73	Covid ward
YORK HOSPITAL	39	Thirty Nine	Geriatric Medicine	70	
SCARBOROUGH HOSPITAL	CHR	Cherry	Acute Internal Medicine	67	
YORK HOSPITAL	AMB	Acute Medical Unit B	Geriatric Medicine	64	
SCARBOROUGH HOSPITAL	MAP	Maple	General Surgery	63	
YORK HOSPITAL	33	Thirty Three	Gastroenterology	61	
SCARBOROUGH HOSPITAL	ITU	Intensive Therapy Unit	Critical Care	58	
YORK HOSPITAL	26	Twenty Six	Trauma And Orthopaedic Surgery	56	
YORK HOSPITAL	25	Twenty Five	Geriatric Medicine	51	
SCARBOROUGH HOSPITAL	CHN	Chestnut	Endocrinology	49	
SCARBOROUGH HOSPITAL	HOL	Holly	Trauma And Orthopaedic Surgery	43	
YORK HOSPITAL	37	Thirty Seven	Geriatric Medicine	41	
YORK HOSPITAL	ASU	Acute Stroke Unit	Geriatric Medicine	41	
SCARBOROUGH HOSPITAL	ASH	Esa	General Medicine	39	
SCARBOROUGH HOSPITAL	CCU	Ccu-Jane Caunt Unit	Cardiology	39	
YORK HOSPITAL	AMU	Acute Medical Unit	Acute Internal Medicine	35	
YORK HOSPITAL	31	Thirty One	Medical Oncology	33	
SCARBOROUGH HOSPITAL	ASP	Aspen Unit	General Medicine	32	
YORK HOSPITAL	16	Sixteen	General Surgery	27	
SELBY WAR MEMORIAL	IPU	Inpatient Unit	Community	26	
YORK HOSPITAL	11	Eleven	General Surgery	25	
YORK HOSPITAL	32	Thirty Two	Cardiology	25	
YORK HOSPITAL	36	Thirty Six	Geriatric Medicine	24	
YORK HOSPITAL	CC	Coronary Care Unit	Cardiology	23	
YORK HOSPITAL	14	Fourteen	Urology	22	
SCARBOROUGH HOSPITAL	AWR	Ann Wright	Geriatric Medicine	21	Pre covid it was high
YORK HOSPITAL	15	Fifteen	Geriatric Medicine	21	
SCARBOROUGH HOSPITAL	STR	Stroke Unit	Geriatric Medicine	19	
SCARBOROUGH HOSPITAL	GRA	Graham	Geriatric Medicine	18	
ST MONICAS	1	St. Monicas	Community	17	
YORK HOSPITAL	IC2	Intensive Care Two	Critical Care	11	
NELSON CT ST HELENS	All Wards (1, 2, HL)	St Helen's Rehabilitation Hospital	Geriatric Medicine / Step Down	10	

Key	
Over 100 deaths	Yellow
70-100 deaths	Blue
50-70 deaths	Purple
30-50 deaths	Green
10-30 deaths	Pink
Under 10 deaths	White



## Appendix O

### Participant Information Sheet, Consent Form, and Questionnaire Content

#### General information about this study:

#### Investigating the relationship between a clinician's personal fears of failure and the delivery of end-of-life care in the workplace

Care at the end of a patient's life is considered one of the most difficult aspects of medical practice. Despite guidance available on best practice, there appears to be several barriers to implementing this guidance when it comes to delivering the news to patients about their prognosis. Exploring psychological processes may offer insight into these barriers and provide ways to support clinical staff and enable more effective end of life conversations and treatment in the future.

#### What is in this questionnaire?

There are three parts to this questionnaire. Firstly, it looks at anxiety and confidence when working with very unwell people. Secondly, it looks at specific feelings around working with death. Thirdly, it looks at a measure of fear of failure.

#### Fear of failure

The questions in the third and final part of this questionnaire have been taken from the Performance Failure Appraisal Inventory. It is a multidimensional measure of fear of failure. It examines fear of failure as a function of person-environment interaction, rather than a trait or state of a person. It recognizes that everyone will experience feelings of failure at points in their life, depending on the environment they are in. It comprises 25-items that measure five dimensions associated with fear of failure: fear of shame and embarrassment, fear of devaluing one's self-estimate, fear of having an uncertain future, fear of important others losing interest and fear of upsetting important others.

The consequences of fear of failure can affect a person's wellbeing, and this in turn can affect their behaviour. Fear of failure has been associated with barriers to achieving goals, a deterioration in mental health and physical health, and can impact moral development and effective problem solving. Although fear of failure, and the impact it has on a person, has been widely studied in business, education and professional sports, it has not yet been used to understand perceptions of success and failure in a medical environment, and the impact it may have on the delivery of clinical practice. This questionnaire will help to develop this area of research.

#### How it could impact you

This questionnaire is anonymous. The researchers conducting this study will not be able to identify any of the participants taking part, and it will have no direct impact on your work or position within the trust. You may find that by taking part in this study you learn about yourself and how fear of failure affects you and the decisions you make.

In the next section we will formally ask you to read the participant information sheet, and then ask you to consent to take part in this research.

#### What you will receive for completing the questionnaire?

At the end of this questionnaire you will have the option to receive a £5 amazon gift voucher for completing the questionnaire in full. You do not have to accept the voucher if you do not wish to. If you do wish to receive the voucher you will be redirected to a new link and will be asked to submit your email address. Your voucher will then be emailed to you when the study closes. Your anonymity will not be affected by requesting a voucher, and your responses cannot be traced back to you. All of your personal details will be held securely by the University of Liverpool.

#### Participant information sheet:

#### Investigating the relationship between a clinician's personal fears of failure and the delivery of end-of-life care in the workplace

You are being invited to take part in a research project. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please do ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### What is the purpose of this research?

We are asking individuals who work with end-of-life patients, and who deliver end of life news to patients. We are looking to understand how you have experienced delivering this news, and also whether you are ever impacted by fear of failure. The aim is for us to understand whether there is a relationship between a fear of failure and having effective end of life conversations.

#### Why have I been invited to take part?

You have been invited to take part as you have been identified as a health worker in a setting where people have been given a terminal prognosis or have died.

#### Do I have to take part?

No. It is up to you to decide whether you agree to take part, and you can change your mind at any time, without giving a reason. If you choose to withdraw you can exit the questionnaire before the end of the questionnaire and your results will not be used for analysis. If you object to participating in the study, it will not impact on your work within the trust.

#### What will happen if I agree to take part?

If you do decide to take part, you will be firstly asked to give your formal consent to take part. If you consent, you will be asked some questions about your age and experience and then you will be asked to complete a questionnaire containing 51 questions. It is expected to last no more than 20 minutes, although you are welcome to use as much time as you need to complete it. You can complete it at a time of your choosing that best suits you. The questionnaire is made up of three questionnaires, the first asking about fear of failure, and then asks about anxiety, confidence, and feelings towards working with people who are dying.

#### What are the potential risks and benefits of taking part?

There are no anticipated risks associated with participation in this research. However, we are aware that for anyone talking about end of life can be distressing. Feelings of distress fluctuate depending on your most recent experiences, and current emotional levels. If you are aware that end of life conversations are particularly difficult for you at this time, you may find some of the questions upsetting. You do not have to complete this questionnaire if you find it too difficult. At the end of the questionnaire there are links to resources and people who can help you if you have found it a difficult or challenging experience. We hope that you will find the process beneficial as an opportunity to reflect on your experiences in relation to how you deliver end of life conversations. We also hope that you will find taking part interesting. The aim of this

work is to help us to further understand how people experience fear of failure, and will hopefully enable us to better support people in the future with having more effective end of life conversations.

What else do I need to know?

What happens if the research stops earlier than expected? Although considered unlikely, should the research stop earlier than planned, we will close the questionnaire link and you will not be able to take part in the research. If you have already taken part and you are affected in any way, we will let you know immediately.

Will my taking part in this project be kept confidential?

All the information that we collect from you during the course of the research will be kept strictly confidential. The questionnaire is completely anonymous, and you will not be identifiable in any reports or publications. You will be assigned a research ID number by the online questionnaire software, so the researchers can identify you throughout the study, but this will not be able to be traced back to you. Some basic demographic information will also be collected from you, but this again will remain anonymous and confidential.

Use of my data

Liverpool Hospitals NHS Foundation Trust and York Hospitals NHS Foundation Trust, as well as some other broader networks of health professionals, are taking part in this study. The University of Liverpool is the sponsor for this study and will act as the data controller for this study. The day to day running of the study is delegated to the researchers, based within the University of Liverpool. We are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained, as we cannot trace the information back to you once you have completed the questionnaire.

Questionnaire responses will be electronically transferred from the Qualtrics website to the University of Liverpool cloud via an internet connection. This data will be going outside the EEU as the questionnaire website is based in America. Data transferred to this website will only be accessible through a password protected login.

The data will be kept by the University of Liverpool for 10 years. The data will be kept securely in a password protected document by the Chief Investigator during this time.

What will happen to the results of the research project?

The results of the research will be used towards a Doctorate in Clinical Psychology thesis and may be published in journals and presented at conferences. Additionally, both NHS trusts involved in the study will be given a summary of results and this information may be disseminated to teams working with end of life patients. No specific data will be traceable to a particular individual or NHS Trust.

Who is responsible for this research?

This research is being carried out by researchers at the University of Liverpool, in conjunction with Liverpool Hospitals NHS Foundation Trust and York Hospitals NHS Foundation Trust palliative services teams.

Who has reviewed the study?

This study has been reviewed by the Chair of the D.Clin.Psychol. Research Review Committee, and was approved on 28th July 2020. It has also been reviewed by the University of Liverpool Board of Sponsorship, and the Health Research Authority (HRA) on 18th December.

Further information and contact details?

If you would like further information about this research, please contact:

John Latham

Email: John.Latham@liverpool.ac.uk

Address: FAO John Latham, Department of Clinical Psychology, Whelan Building, University of Liverpool, Liverpool, L69 3DT.

**CONSENT FORM**

IRAS ID: 289310  
Study Number: UoL001588

Title of Project: Investigating the relationship between a clinician's personal fears of failure and the delivery of end-of-life care in the workplace

Name of principle researcher: John Latham

Please answer either yes or no to each question:

1. I confirm that I have read the information sheet for the above study, I am aware that I have the right to contact the researcher and have the opportunity to consider the information with them and ask questions about the research and how data will be collected and handled within it. (1)	▼ Yes (1) ... No (2)
2. I understand that my questionnaire responses will be electronically transferred from the Qualtrics website to the University of Liverpool cloud via an internet connection and that this data will be going outside the EEU as the questionnaire website is based in America. Data transferred to this website will only be accessible through a password protected login. (3)	▼ Yes (1) ... No (2)
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my work or legal rights being affected. (2)	▼ Yes (1) ... No (2)

Q1A I agree to take part in the above study.

Yes (1)

No (2)

Questionnaire

---

Start of Block 1: About you and your experience

Q1.1 What is your NHS trust?

- Liverpool Hospitals FT (1)
- York & Scarborough Hospitals FT (2)
- Other FT (3)
- 

Q1.2 What is your gender?

- Male (1)
- Female (2)
- Other (3)
- I wish to not disclose (4)
- 

Q1.3 What is your role?

- Doctor (1)
- Specialist Nurse (2)
- Other (3) \_\_\_\_\_
- 

Q1.4 What is your grade/band? (if you would rather not say or this is not applicable for your role please put 'n/a')

\_\_\_\_\_

---

Q1.5 How many years of experience do you have working in your role?

- 0-1 (1)
- 1-3 (2)
- 3-5 (3)
- 5-10 (4)
- 10-15 (5)
- 15-30 (6)
- 30+ (7)
-

Q1.6 What is your area of specialism within the hospital / your setting? (if you would rather not say please put 'n/a')

---

Q1.7 Using the predefined groups below, please estimate how many times per month you have end of life conversations:

- Less than one (1)
- 1-2 (2)
- 2-5 (3)
- 5-10 (4)
- 10-12 (5)
- More than 12 (6)

End of Block: About you and your experience

Start of Block: SEPC

**Defining 'end of life' - something to consider before you begin this questionnaire**

When we refer to 'end of life' in this questionnaire this could include patients who you may describe as:

- 'Dying'
- 'Terminal'
- 'Palliative'
- Where there is 'no more active treatment'
- 'Incurable'
- Receiving 'best supportive care'

We also include the phrase 'living with a life limiting illness' as part of an end-of-life conversation if the patient is told that no treatment will result in a substantial cure.

Please click the arrow to continue.

**Question Block 2: SEPC**

Q2.1

Presented are a series of statements that relate to issues and experiences that may be encountered when working with someone in the end stages of their life. When answering the questions, we would like you to imagine how you think you would feel in relation to the issues and situations presented.

In this next section the statements relate to communication issues that may be encountered within medical settings.

Please answer the following questions by moving the scale on the line between "very anxious" and "very confident" in relation to how you would feel.

An example is:

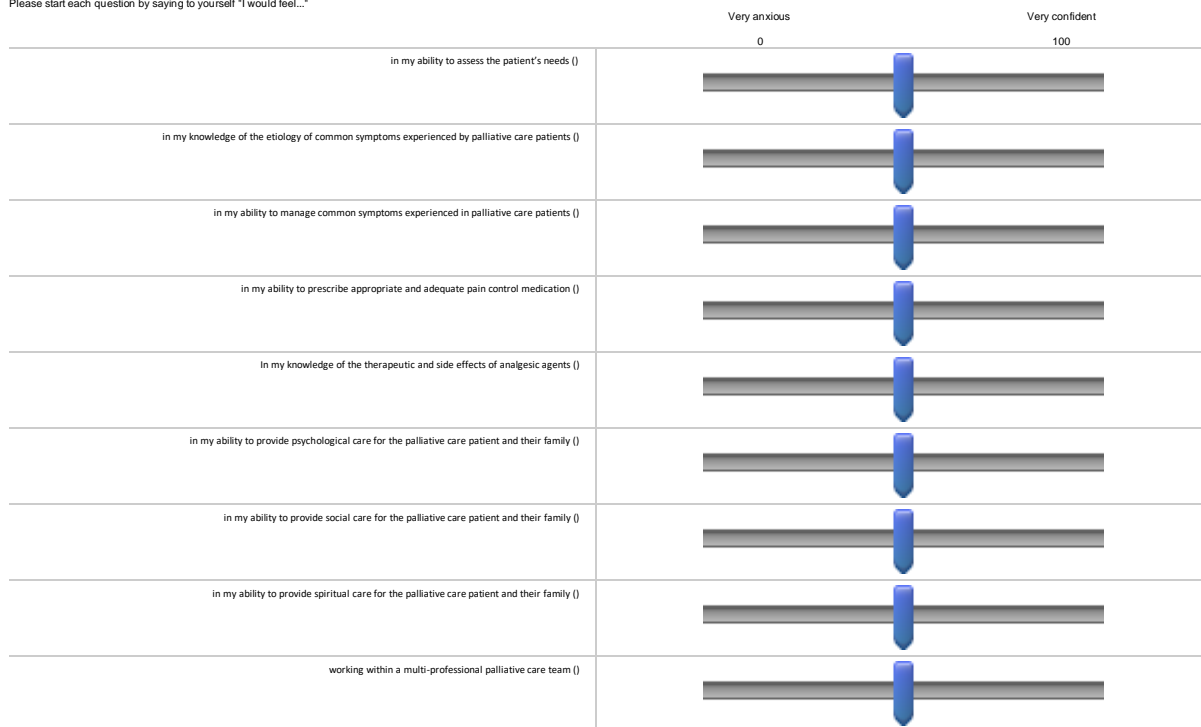
'I would feel [very anxious - very confident] having a conversation with a dying patient. Please start each question by saying to yourself "I would feel..."'

	Very anxious 0	Very confident 100
discussing the likely effects of a possible terminal illness with the patient ()		
discussing the likely effects of a possible terminal illness with the patient's family ()		
discussing issues of death and dying ()		
discussing the patient's own death (with the patient) ()		
discussing the patient's imminent/anticipated death with the family ()		
discussing the patient's death with the family upon bereavement ()		
answering the patient's question "How long have I got to live?" ()		
answering the patient's question "Will there be much suffering or pain?" ()		

Q2.2

The following statements relate to communication issues that may be encountered within medical settings.

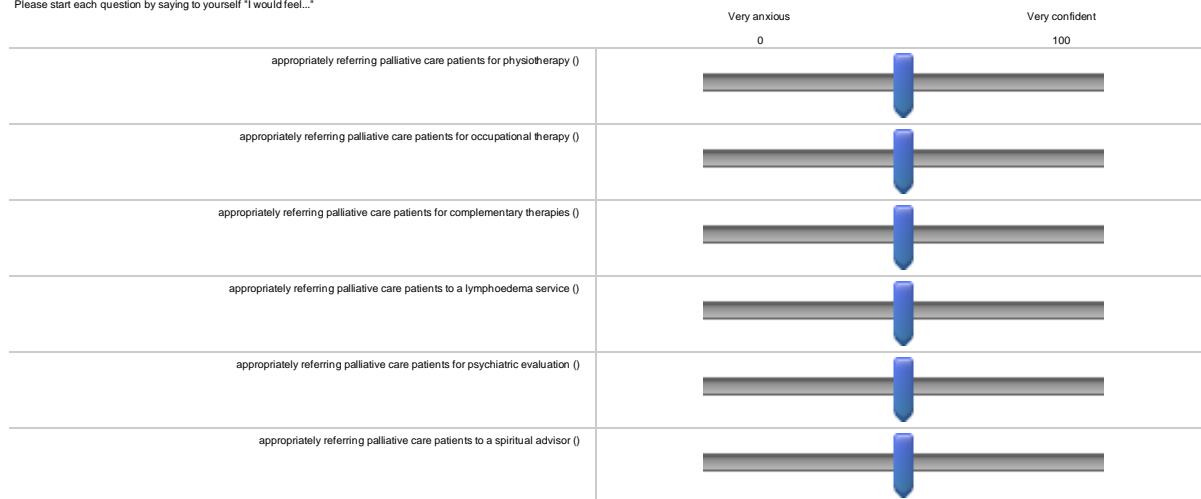
Please start each question by saying to yourself "I would feel..."



Q2.3

The following statements relate to communication issues that may be encountered within medical settings.

Please start each question by saying to yourself "I would feel..."



End of Block: SEPC

**Just a reminder:**

When we refer to 'end of life' in this questionnaire this could include patients who you may describe as:

- 'Dying'
- 'Terminal'
- 'Palliative'
- Where there is 'no more active treatment'
- 'Incurable'
- 'Receiving best supportive care'

We also include 'living with a life limiting illness' as part of an end of life conversation if the patient is told that no treatment will result in a substantial cure.

Please click the arrow to continue.

Start of Block: Thanatophobia scale

**Question Block 3: Thanatophobia Scale**

Q3 Please select the answer that corresponds to how strongly you agree or disagree with the following statements. Answer according to how you think you would feel regarding the issues and situations presented below: Presented are a series of statements that relate to issues and experiences that may be encountered when working with someone in the end stages of life. When answering the questions, we would like you to imagine how you think you would feel in relation to the issues and situations presented.

Please select the answer that corresponds to how strongly you agree or disagree with the following statements:

	Strongly disagree (1)	Disagree (2)	Somewhat disagree (3)	Neither agree nor disagree (4)	Somewhat agree (5)	Agree (6)	Strongly agree (7)
Dying patients make me feel uneasy... (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel pretty helpless when I have terminal patients on my ward... (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is frustrating to have to continue talking with relatives of patients who are not going to get better... (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Managing dying patients traumatizes me... (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It makes me uncomfortable when a dying patient wants to say goodbye to me... (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't look forward to being the personal physician of a dying patient... (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When patients begin to discuss death, I feel uncomfortable... (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Question Block 4: COVID-19 adaption**

Q4 Please describe your experience of communicating about end of life prognosis during the Covid-19 pandemic? (if this is irrelevant to you, please put 'n/a')

---

End of Block: Thanatophobia scale

Start of Block: The Performance Failure Appraisal Inventory

**Question Block 5: PFAI**

Q5 The next section is looking to understand fear of failure and how you might experience this across your life. This measure has been included to identify any links between fear of failure and end of life clinical practice.

Please read the following questions and score each one based on how much you personally believe the statement. Remember, no one else will see your responses, and so please be honest in your responses.

	Do not believe at all (-2)	Believe it 25% of the time (-1)	Believe it 50% of the Time (0)	Believe it 75% of the time (1)	Believe it 100% of the time (2)
When I am failing, it is often because I am not smart enough to perform successfully. (5.1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, my future seems uncertain. (5.2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, it upsets important others. (5.3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, I blame my lack of talent. (5.4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, I believe that my future plans will change. (5.5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, I expect to be criticized by important others. (5.6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, I am afraid that I might not have enough talent. (5.7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, it upsets my "plan" for the future. (5.8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, I lose the trust of people who are important to me. (5.9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am not succeeding, I am less valuable than when I succeed. (5.10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am not succeeding, people are less interested in me. (5.11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, I am not worried about it affecting my future plans. (5.12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am not succeeding, people seem to want to help me less. (5.13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, important others are not happy. (5.14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am not succeeding, I get down on myself easily. (5.15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, I hate the fact that I am not in control of the outcome. (5.16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am not succeeding, people tend to leave me alone. (5.17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, it is embarrassing if others are there to see it. (5.18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, important others are disappointed. (5.19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

When I am failing, I believe that everybody knows I am failing. (5.20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am not succeeding, some people are not interested in me anymore. (5.21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, I believe that my doubters feel that they were right about me. (5.22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am not succeeding, my value decreases for some people. (5.23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, I worry about what others think about me. (5.24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am failing, I worry that others may think I am not trying. (5.25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: The Performance Failure Appraisal Inventory

Start of Block: Block 6 – Final messages

Q6.1 You have now completed the questionnaire. Thank you for your time.  
 To claim your £5 amazon voucher please click the link here, and you will be asked to submit your email address. Your amazon voucher will be sent to you digitally at the end of the study. [LINK] If you have been affected by any of the questions in this questionnaire please consider contacting your staff support team using the following contact details or refer to the self-help materials listed.

If you work within York Hospitals NHS Foundation Trust please visit: <https://www.yorkhospitals.nhs.uk/work-with-us/staff-benefits-and-wellbeing/wellbeing-team/information/>

If you work within Liverpool Hospitals NHS Foundation Trust please visit: <https://www.aintreehospital.nhs.uk/our-organisation/corporate-support-departments/people-and-corporate-affairs/human-resources/occupational-health-and-wellbeing/>

A number of downloadable comprehensive self help materials exist to help you understand and manage distress. Please visit <https://www.cci.health.wa.gov.au/Resources/Looking-After-Yourself> for a range of helpful resources.

The Samaritans are a confidential support for people experiencing feelings of distress or despair.  
 Phone: 116 123 (free 24-hour helpline)  
 Website: [www.samaritans.org.uk](http://www.samaritans.org.uk)

For further services that could help you visit this link: <https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/>

<https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/>

If you wish to discuss specific issues raised by this questionnaire you are welcome to contact the lead researcher, or the trust key contacts as per below:

Primary Investigator:  
 John Latham  
 Email: [john.latham@liverpool.ac.uk](mailto:john.latham@liverpool.ac.uk)

Liverpool Hospitals NHS FT key partner: Dr Victoria Molyneux: [Victoria.Molyneux@liverpoolft.nhs.uk](mailto:Victoria.Molyneux@liverpoolft.nhs.uk)  
 York Hospitals NHS FT key partner: Kathryn Sartan: [Kathryn.Sartan@york.nhs.uk](mailto:Kathryn.Sartan@york.nhs.uk)

End of Block: Block 4



## Appendix P

**Table P1**

*Primary Regression Analysis*

Dependent Variable	Variable	Step 1						Step 2					
		Cumulative		Simultaneous				Cumulative		Simultaneous			
		Adjusted R <sup>2</sup>	Model Fit	β	95% C.I.		p	Adjusted R <sup>2</sup>	Model Fit	β	95% C.I.		p
Lower	Upper				Lower	Upper							
Communication (DV1)		0.082	F (4,198) = 5.53, p<.001										
	Gender			3.585	-3.96	11.14	0.350			3.587	-3.98	11.16	0.351
	Role			2.072	-5.37	9.51	0.583			2.130	-5.35	9.61	0.575
	Years of experience			0.510	-1.56	2.58	0.628			0.537	-1.56	2.63	0.614
	Number of end-of-life conversations per month			4.654	2.47	6.84	<.001			4.653	2.46	6.85	<.001
	Fear of Failure score (PFAI)								0.078	F (5,197) = 4.41, p<.001	0.399	-3.69	4.49
Decision-making (DV2)		0.088	F (4,198) = 5.87, p<.001										
	Gender			3.025	-3.73	9.78	0.378			3.031	-3.73	9.79	0.378
	Role			0.523	-6.13	7.17	0.877			0.701	-5.98	7.38	0.836
	Years of experience			-0.845	-2.70	1.01	0.369			-0.763	-2.63	1.11	0.422
	Number of end-of-life conversations per month			4.625	2.67	6.58	<.001			4.624	2.67	6.58	<.001
	Fear of Failure score (PFAI)								0.0854	F (5,197) = 4.77, p<.001	1.226	-2.43	4.88
Working with others (DV3)		0.024	F (4,198) = 2.22, p=0.068										
	Gender			3.233	-4.129	10.59	0.388			3.234	-4.146	10.61	0.389
	Role			1.268	-5.983	8.52	0.731			1.301	-5.991	8.59	0.725
	Years of experience			-0.481	-2.499	1.54	0.639			-0.465	-2.507	1.58	0.653
	Number of end-of-life conversations per month			2.951	0.819	5.08	0.007			2.951	0.813	5.09	0.007
	Fear of Failure score (PFAI)								0.019	F (5,197) = 1.77, p=0.120	0.227	-3.762	4.22
Comfortableness (DV4)		0.116	F (4,198) = 7.65, p<.001										
	Gender			-4.560	-7.588	-1.532	0.003			-4.558	-7.593	-1.523	0.003
	Role			-3.663	-6.645	-0.678	0.016			-3.612	-6.611	-0.614	0.018
	Years of experience			0.313	-0.517	1.144	0.458			0.337	-0.503	1.176	0.430
	Number of end-of-life conversations per month			-0.876	-1.753	0.001	0.050			-0.876	-1.755	0.003	0.051
	Fear of Failure score (PFAI)								0.113	F (5,197) = 6.13, p<.001	0.347	-1.293	1.988

*Note.* Regression analysis showing Gender, Role, Years of experience, Number of EOL conversations, and FOF score as predictors of each dependent variable, to three decimal places.

### Appendix Q

**Table Q1**

*Exploratory Regression Analysis*

Dependent Variable	Variable	Step 1					Step 2 – Individual PFAI factors						
		Cumulative		Simultaneous			Cumulative		Simultaneous				
		Adjusted R <sup>2</sup>	Model Fit	β	95% C.I.		p	Adjusted R <sup>2</sup>	Model Fit	β	95% C.I.		P
				Lower	Upper					Lower	Upper		
Communication (DV1)		0.083	F (4,200) = 5.63, p<.001										
	Gender			2.960	-3.600	9.520	0.375			0.971	-5.332	7.280	0.762
	Role			2.319	-4.810	9.440	0.522			1.802	-5.015	8.620	0.603
	Years of experience			0.504	-1.550	2.560	0.630			0.406	-1.555	2.370	0.684
	Number of end-of-life conversations per month			4.718	2.570	6.870	<.001			4.286	2.245	6.330	<.001
	FSE						0.181	F (9,195) = 6.01, p<.001	3.125	-0.027	6.220	0.048	
	FDSE									-3.341	-8.706	2.020	0.221
	FUF									-0.211	-5.793	5.370	0.941
	FIOLI									-6.735	-12.034	-1.440	0.013
FUIO									1.250	-4.605	7.110	0.674	
Decision-making (DV2)		0.089	F (4,200) = 5.98, p<.001										
	Gender			2.443	-3.420	8.310	0.412			0.718	-5.053	6.488	0.807
	Role			0.884	-5.530	7.210	0.795			1.104	-5.137	7.345	0.728
	Years of experience			-0.834	-2.670	1.000	0.372			-1.066	-2.861	0.730	0.243
	Number of end-of-life conversations per month			4.680	2.760	6.600	<.001			4.376	2.508	6.244	<.001
	FSE						0.147	F (9,195) = 4.90, p<.001	2.445	-0.391	5.282	0.091	
	FDSE									-7.887	-12.799	-2.976	0.002
	FUF									1.211	-3.899	6.320	0.641
	FIOLI									-1.175	-6.026	3.676	0.633
FUIO									2.093	-3.267	7.453	0.442	
Working with others (DV3)		0.025	F (4,200) = 2.28, p<.062										
	Gender			1.438	-4.970	7.850	0.659			0.272	-6.133	6.676	0.933
	Role			2.259	-4.700	9.220	0.523			2.173	-4.754	9.100	0.537
	Years of experience			-0.445	-2.450	1.560	0.663			-0.597	-2.590	1.396	0.555
	Number of end-of-life conversations per month			3.120	1.020	5.220	0.004			2.824	0.751	4.898	0.008
FSE						0.057	F (9,195) = 2.38, p<.014	2.062	-1.086	5.211	0.198		

Dependent Variable	Variable	Step 1						Step 2 – Individual PFAI factors						
		Cumulative		Simultaneous				Cumulative		Simultaneous				
		Adjusted R <sup>2</sup>	Model Fit	β	95% C.I.		p	Adjusted R <sup>2</sup>	Model Fit	β	95% C.I.		P	
				Lower	Upper				Lower	Upper				
	FDSE	0.110	F (4,200) = 7.33, p<.001					0.164	F (9,195) = 5.46, p<.001	-5.873	-11.325	-0.422	0.035	
	FUF									0.4.33	-5.238	6.104	0.881	
	FIOLI										-4.031	-9.415	1.353	0.141
	FUIO										5.372	-0.577	11.321	0.076
Comfortableness (DV4)	Gender	0.110	F (4,200) = 7.33, p<.001	-3.763	-6.401	-1.124	0.005	0.164	F (9,195) = 5.46, p<.001	-3.106	-5.706	-0.505	0.019	
	Role			-4.014	-6.880	-1.148	0.006			-3.839	-6.651	-1.027	0.008	
	Years of experience			0.315	-0.513	1.142	0.454			0.313	-0.496	1.122	0.447	
	Number of end-of-life conversations per month			-0.955	-1.820	-0.091	0.030			-0.845	-1.687	-0.004	0.049	
	FSE													
	FDSE								-1.117	-2.395	0.161	0.086		
	FUF								0.013	-2.200	2.226	0.990		
	FIOLI								0.784	-1.518	3.086	0.503		
	FUIO								1.923	-0.262	4.109	0.084		
									0.333	-2.082	2.748	0.786		
SEPC total score (Exploratory DV)	Gender	0.082	F (4,200) = 5.54, p<.001	2.280	-3.270	7.830	0.419	0.155	F (9,195) = 5.14, p<.001	0.654	-4.758	6.065	0.812	
	Role			1.807	-4.220	7.830	0.555			1.693	-4.159	7.545	0.569	
	Years of experience			-0.258	-2.000	1.480	0.770			-0.419	-2.103	1.265	0.624	
	Number of end-of-life conversations per month			4.173	2.360	5.990	<.001			3.829	2.077	5.580	<.001	
	FSE													
	FDSE								2.544	-0.115	5.204	0.061		
	FUF								-5.701	-10.306	-1.095	0.016		
	FIOLI								0.477	-4.314	5.268	0.844		
	FUIO								-3.980	-8.529	0.568	0.086		
									2.905	-2.121	7.931	0.256		

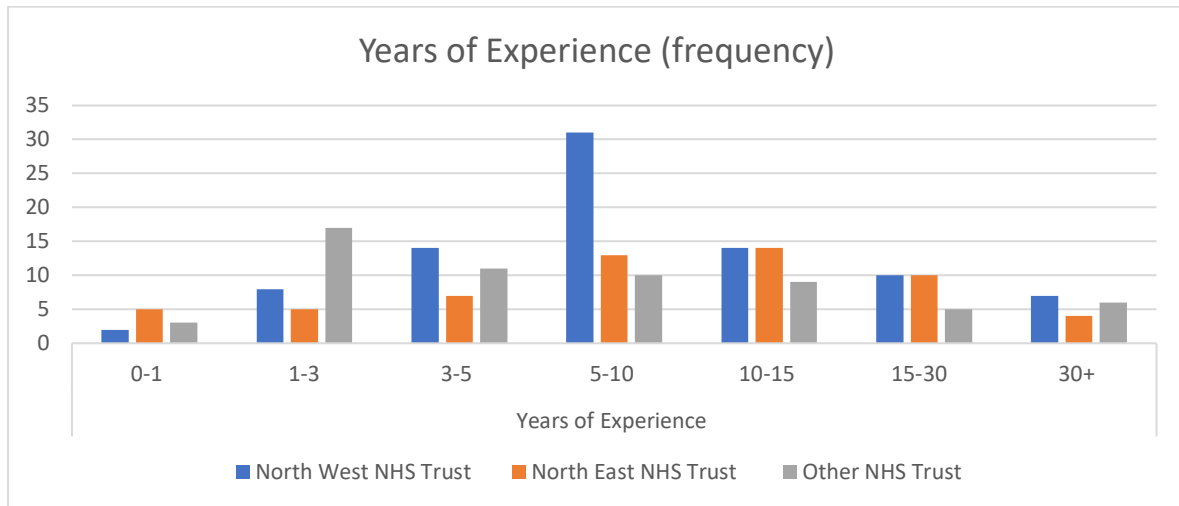
Note. Regression analysis showing Gender, Role, Years of experience, Number of EOL conversations, and the five subscales of the PFAI as predictors of each dependent variable, as well as total SEPC score as an exploratory dependent variable, to three decimal places.

## Appendix R

### Empirical Paper Figures

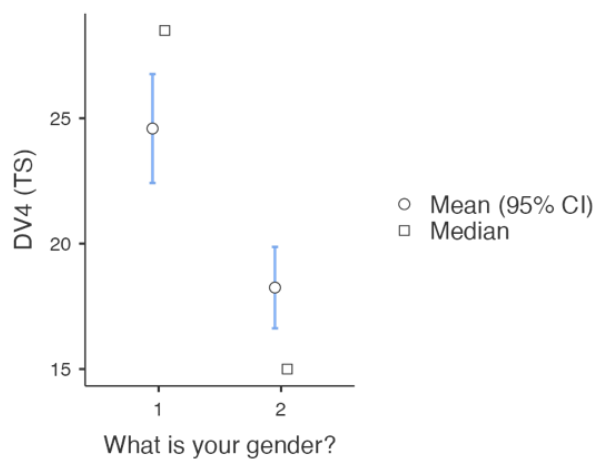
**Figure R1**

*Clinician Years of Experience by NHS Trust*



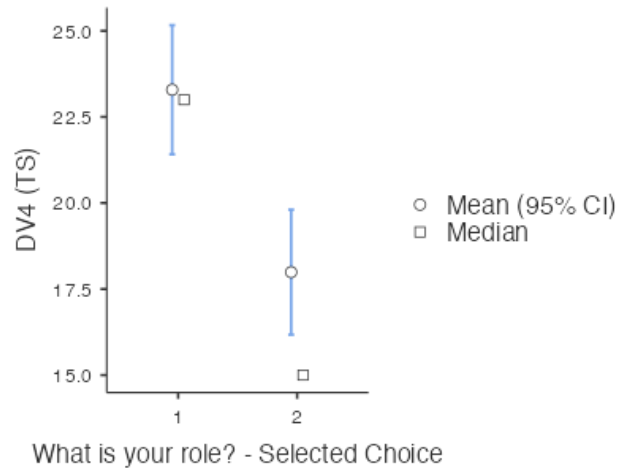
**Figure R2**

*Mann-Whitney U Comparison of Male (1) and Female (2) Thanatophobia Scores (DV4)*



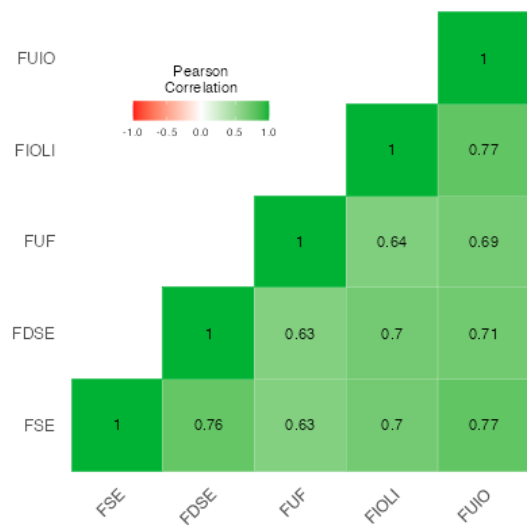
**Figure R3**

*Mann-Whitney U Comparison of Doctors (1) and Nurses (2) Thanatophobia Score (DV4)*



**Figure R4**

*Correlation Heatmap for the Five Subscales of PFAI*



## Appendix S

**Table S1**

### Amendment History

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made
1	3.3	27.01.21	JL	Minor changes only affecting the layout of the questionnaires and how they will be coded subsequently (additions to proposal highlighted in yellow).
2	3.4	30.03.21	JL	<ol style="list-style-type: none"> <li>Item 7.3.2.3 updated wording of time scale statement to allow for a broader number of responses (p12).</li> <li>Update on IRAS form and participant info sheet (p19) to change Trust based investigator for Liverpool NHS FT from Stephen Mason to Victoria Molyneux.</li> </ol>



John Latham  
Clinical Psychology Trainee  
Doctorate in Clinical Psychology Programme  
University of Liverpool  
L69 3GB

D.Clin.Psychology Programme  
Division of Clinical Psychology  
Whelan Building, Quadrangle  
Brownlow Hill  
LIVERPOOL  
L69 3GB  
Tel: 0151 794 5530/5534/5877  
Fax: 0151 794 5537  
[www.liv.ac.uk/dclinpsychol](http://www.liv.ac.uk/dclinpsychol)

1 February 2021

**RE:** To investigate whether a clinician's personal fears of failure related to confidence in and comfort with the delivery of end-of-life care, using a combination of standardised measures

**Trainee:** John Latham

**Supervisors:** Sarah Butchard, Luna Centifanti, Stephen Mason

Dear Johnny,

Thank you for your notification of amendment to your proposal submitted to the Chair of the D.Clin.Psychol. Research Review Committee.

I can now confirm that your amended proposal (*version number 3.3, dated 27/01/2021*) meets the requirements of the committee and have been approved by the Committee Chair.

Please take this Chairs Action decision as **final** approval from the committee.

You may now progress to the next stages of your research.

I wish you well with your research project.

Dr Anam Elahi  
Vice Chair D.Clin.Psychol. Research Review Committee

A member of the Russell Group  
Dr Laura Golding Programme Director  
Dr Gunduli Kemele Academic Director  
Dr Jim Williams Joint Clinical Director  
Dr Beth Greenhill Joint Clinical Director  
Dr Ross White Research Director  
Mrs Sue Knight Programme Co-ordinator



Johnny Latham  
Clinical Psychology Trainee  
Doctorate in Clinical Psychology Programme  
University of Liverpool  
L69 3GB

D.Clin.Psychology Programme  
Division of Clinical Psychology  
Whelan Building, Quadrangle  
Brownlow Hill  
LIVERPOOL  
L69 3GB  
Tel: 0151 794 5530/5534/5877  
Fax: 0151 794 5537  
[www.liv.ac.uk/dclinpsychol](http://www.liv.ac.uk/dclinpsychol)

8 April 2021

**RE:** To investigate whether a clinician's personal fears of failure related to confidence in and comfort with the delivery of end-of-life care, using a combination of standardised measures

**Trainee:** Johnny Latham

**Supervisors:** Sarah Butchard, Luna Centifanti and Stephen Mason

Dear Johnny,

Thank you for your notification of amendment to your proposal submitted to the Chair of the D.Clin.Psychol. Research Review Committee.

I can now confirm that your amended proposal (*version number 3.4, dated March 2021*) meets the requirements of the committee and have been approved by the Committee Chair.

Please take this Chairs Action decision as **final** approval from the committee.

You may now progress to the next stages of your research.

I wish you well with your research project.

Dr Steven Gillespie  
Vice Chair D.Clin.Psychol. Research Review Committee

A member of the Russell Group  
Dr Laura Golding Programme Director  
Dr Gunduli Kemele Academic Director  
Dr Jim Williams Joint Clinical Director  
Dr Beth Greenhill Joint Clinical Director  
Dr Ross White Research Director  
Mrs Sue Knight Programme Co-ordinator