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MAJOR RESEARCH PROJECT

A QUALITATIVE EXPLORATION OF THE EXPERIENCES OF PALLIATIVE CARE  
STAFF WHEN WORKING WITH DEATH AND DYING

**Section A: What is the experience of staff working in palliative care? A systematic  
review and thematic synthesis.**

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**Section B: Palliative care nurses' experience of interpersonal challenges with dying  
patients: An interpretative phenomenological analysis and psychodynamic exploration.**

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Finally, a word for my father who, during the course of this project became seriously unwell and sadly died. In attending to his palliative needs I discovered for myself just how powerful, how devastating, and how overwhelmingly affirming it can feel to *be with* someone at the end of their life.

## Summary of MRP portfolio

**Section A** provides a review of the literature of the experience of staff working in palliative care. The review summarises, critiques, and synthesises fourteen papers matching the inclusion and quality criteria. Papers are reviewed in light of their methodological strengths and limitations. Thematic synthesis of the findings yielded four key themes, and clinical and research implications are discussed.

**Section B** describes a qualitative study that explores palliative care nurses' experience of interpersonal challenges with dying patients. Seven semi-structured interviews were conducted and analysed using Interpretative Phenomenological Analysis and psychodynamic exploration. Three superordinate themes and related subthemes are described and discussed. Limitations and clinical and research implications for future research are outlined.

**Section C** provides supporting documentation

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**MAJOR RESEARCH PROJECT**

**SECTION A: LITERATURE REVIEW**

**What is the experience of staff working in palliative care? A systematic review and thematic synthesis.**

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## Abstract

**Background:** Factors affecting individuals who work in palliative care are complex, individual, and subtle, and can lead to serious issues such as burnout or staff leaving post if the experiences of staff are not carefully understood.

**Aims:** Review the qualitative literature with a view to answering the question ‘what can be learned about the experience of working in palliative care?’

**Design:** Four databases were searched systematically and reference lists of retrieved papers were scanned

**Findings:** Fourteen papers matched inclusion and quality criteria. Thematic synthesis of the findings yielded four key themes: The personal and the relational experience; the organisational experience; coping with death and, defensive processes.

**Clinical and research implications:** Useful implications for clinical practice centred primarily on the domain of staff support and space for reflection, whilst several future research recommendations were made.

## **Introduction**

### **Palliative care context**

Palliative care is an approach which aims to improve or relieve the suffering of patients and their families in the context of life-threatening illness; encompassing the assessment and treatment of physical, psychological, social, and spiritual needs (Rome, Luminais, Bourgeois, & Blais, 2011). It has become synonymous with specialist care for those who are dying (Curren, 2001, p. 2). This defining feature thus distinguishes it from other forms of healthcare which, either explicitly or implicitly, are interested only in curing illness entirely, and in preserving, or saving life (Quinn, 2005, p. 1).

In the face of a life-threatening illness, it is both natural and understandable for patients to feel a slew of tensions and emotions such as grief, sadness, despair, anger, pain, anxiety, dependency and vulnerability (Rodin & Zimmermann, 2008), inevitably taking time to process and accept. Feely, Havyer, Lapid, and Swetz (2013) suggest that beyond these emotional reactions, many can achieve some sense of acceptance, comfort, and coping through the dying process. However, the dying process can be complicated and arriving at a point of 'acceptance' is itself a notion for careful thought and consideration.

Since Freud (1915), psychoanalytic writers such as Becker (1973), and Langs (1997) have asserted that the human relationship to death - and the anxiety that mortality generates - is a "universally and inherently irresolvable issue" (Langs, 1997, p. 62) typically culminating in a state of denial. If true, it would bring to question any perception of 'acceptance' around death, whether from the onlooker or from the dying individual themselves. That said, Rodin and Zimmermann (2008) acknowledge that much of the writing on the human relationship to death and mortality is not necessarily meant to apply to populations who are literally at the

end of their life (p. 183), but rather more concerned with fear of death in one's internal world, which may be distinct from their external reality. Kubler-Ross (1975) suggested that whilst we do exist in a fundamentally death-denying society, at the end of life there appears to be a process through which individuals adapt to terminal disease, ultimately arriving at a place of acceptance. This dichotomous description underestimates the fluctuating nature of self-states (Klein, 2002) and the fact that the desire to live and 'look away' from death may in fact coexist with the increasing recognition that the end of life is approaching (Rodin, Zimmermann, et al., 2007). So, rather than a linear journey from denial to acceptance, it is more likely that individuals oscillate between states and that the dying trajectory is mediated by a person's history; their relationships, experiences of care, self-concept, and personality style (Katz & Genevay, 2002, p. 327).

### **Caring in palliative care**

The experience of dying is made yet more complex when considered in the cultural and relational context in which it occurs. Psychodynamic theories (e.g. Object Relations Theory, Klein 2002) posit that the emotional worlds of individuals do not exist in isolation but are felt and experienced in *relationship* with others (both consciously and unconsciously). Ashby (2017) said of the palliative care context, specifically:

*“As unconscious transactions between client and carer are usually not understood, the two-way street is not noticed. A dying person's fears may be projected on to team members and teams themselves. Indeed, it is said that patients make us feel what they cannot tell us (Carroll, 2014) ... pain and negative emotions have to 'go' somewhere, and in human psychodynamics, they 'go' into and through those who care”*  
(Ashby, 2017, p. 213).

It is with this perspective that one can begin to appreciate some of the powerful forces operating in palliative care settings, and in his chapter on working with dying people, Speck (1994, p. 94) acknowledged the enormous challenges faced by staff in palliative care. Menzies (1960) recognised that nursing patients who have incurable diseases is one of the most distressing tasks for staff; confronted by the threat and reality of suffering in a way which few lay people are. Work which inevitably arouses strong and mixed feelings of pity, compassion, love, guilt and hatred; resentment of the patients who arouse these feelings, and envy of the care afforded to them (p. 98). Menzies continues to describe the ways that that systems *as a whole* seem to function in a way which parallels the individual experience - where defensive strategies help teams to perform the primary task of 'care' whilst at the same time 'looking away' from the difficult personal emotional reality of their patients' experiences. These psychosocial processes operating within an organisational context can become the foundations for what Hinshelwood and Skogstad (2000) described as a *defensive culture*, where unconscious defences contribute to a set of implicit operating procedures which influence roles, tasks, authority and leadership. A contemporary revisiting of Menzies' seminal work found that much of its thesis remains relevant, highlighting, for example, the way emphasis on target and increases in work volume does not seem to take account of the psychological impact of such changes on the staff who work in these services (Lawlor, 2009).

A survey of hospice and palliative care clinicians found that this cost of caring contributes to gifted clinicians leaving post, further damaging the functioning of the team and ultimately affecting client care (Swetz, Harrington, Matsuyama, Shanafelt, & Lyckholm, 2009; West et al., 2006). Palliative care can be particularly vulnerable to these outcomes as a reflection of practitioners needing to find a level of compassion, patient after patient, in the midst of overwhelming suffering (Edmonds, Yeung, Onderdonk, Mitchell, & Thornberry, 2015, p.274). That said, Menzies' (1960) findings about the defensive culture of nursing were

seminal in the recognition that staff need the opportunity to process the impact that the work is having on them (Lawlor, 2009).

The theoretical and empirical literature described here indicates that in the complex relational milieu of palliative care, staff are likely to experience a range of tensions; from patients, from the organisation, and also from within (as described by Speck, 1994). Several studies have sought to review the mainly quantitative findings centring on issues such as staff burnout (Martins Pereira, Fonseca, & Sofia Carvalho, 2011) and coping and resilience (e.g. Gillman et al., 2015; Zanatta, Maffoni, & Giardini, 2019), which go some way towards understanding the challenges that staff experience in palliative care. From such endeavours, interventions have been developed aimed at preventing burnout (e.g. Back, Steinhauser, Kamal, & Jackson, 2016).

However, it has also been acknowledged that the factors affecting individuals who work in palliative care - ultimately contributing to issues such as staff burnout - are complex, individual, and subtle (Martins Pereira, Fonseca, & Sofia Carvalho, 2011) indicating a need to attend also to the qualitative research which explicitly attempts to capture such subtlety of experience. A recent review of the qualitative literature aimed to understand the nature and definition of resilience in palliative care, from the perspective of nurses (Powell, Froggatt, & Giga, 2019), though by focusing primarily on 'resilience' and 'nursing' there remain questions unanswered about what is experienced more broadly by the staff. To our knowledge there is a lack of sensitivity in the review literature for the lived *experience* of staff; literature which attempts to capture and summarise what it is *like* from the perspective of those working in palliative care, without constraining their explorations by specific constructs such as 'resilience', or 'coping', or 'burnout'.



## **Aim of review**

The aim of this paper, then, is to critically review the qualitative literature surrounding the experience of staff working in palliative care settings with a view to answering the question ‘what can be learned about the experience of working in palliative care’? It will further aim to explore the implications of the existing literature whilst identifying areas for further research.

## **Review scope and structure**

The present review aimed to systematically examine the extant literature for qualitative articles concerning the experience of staff working in palliative care. Once examined, the selected articles were each subject to quality appraisal before thematic synthesis (Thomas & Harden, 2008) was conducted. All processes are described below for transparency and rigour.

## **Methodology**

### **Topical boundaries, inclusion, and exclusion criteria**

The present review sought to understand the experiences of health care staff working in dedicated palliative care teams, reflective of the fact that this group will engender a degree of peculiarity and homogeneity sufficient that the experiences described can be usefully synthesised. The experience of other staff groups who also have contact with end-of-life care, such as ICU staff, for example, will probably be different for many reasons, not least that their primary focus is to save or preserve life, whereas palliative care teams operate on the basis of a different relationship to life and death (Quinn, 2005).

Another topical boundary established for the purposes of this report is the unique use of the term ‘experience’, at the expense of similar terms such as ‘attitudes’, ‘perception’, ‘views’, ‘knowledge’, ‘involvement’ etc. These alternative terms were excluded from the search as they reflect concepts for understanding which are qualitatively too far removed from the focus of this review. Experience was chosen alone as a search term which uniquely captures the participant’s lived, emotionally-felt contact with/participation in a given phenomenon. The American Psychological Association dictionary defines experience as events that have been *lived through*, and which contribute to the present contents of *consciousness* (American Psychological Association, 2020). Whilst other dictionary definitions emphasise *impressions* as a result of *direct contact*. Indeed there may be other terms which have semantic overlap with ‘experience’, but for the purposes of the present review, experience was chosen alone.

The SPIDER tool (Cooke, Smith, & Booth, 2012) was used to clarify the search strategy for this review. When under evaluation the SPIDER tool was found to be easy, effective, and comparatively more appropriate when conducting qualitative literature searches (Cooke, Smith, & Booth, 2012)

The review included articles which met the following criteria.

Table 1.

*Search strategy according to Cooke, Smith and Booth’s (2012) SPIDER tool*

<b>Category</b>	<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Sample	<ul style="list-style-type: none"> <li>Studies which included participants who are health professionals working in palliative care teams</li> </ul>	<ul style="list-style-type: none"> <li>Studies which do not involve staff, or where the staff experience is not the primary focus</li> <li>Studies which include staff who work with children</li> <li>Studies whose focus is not primarily with participants who work in a palliative care team</li> </ul>

Phenomena of interest	<ul style="list-style-type: none"> <li>• Palliative care</li> <li>• Staff experience</li> </ul>	<ul style="list-style-type: none"> <li>• Any research whose focus was not centred around the concept of ‘experience’</li> <li>• Any research which did not include the terms ‘palliative’ or ‘experience’ in the title to ensure sufficient focus</li> </ul>
Design	<ul style="list-style-type: none"> <li>• Focused on qualitative data, including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, and narrative approaches were considered</li> </ul>	<ul style="list-style-type: none"> <li>• All other designs</li> <li>• Studies which did not satisfy the quality standards as determined by the CASP qualitative checklist</li> <li>• Studies which were appraised to have lacked opportunity for depth of enquiry, follow-up questions, and/or content clarification during in the data collection process. The absence of the above has the potential to miss important nuances and detail of the lived experience.</li> </ul>
Evaluation	<ul style="list-style-type: none"> <li>• The research should make an attempt to capture the <i>experience</i> of the staff involved in palliative care rather than merely describing a process, framework, or intervention.</li> <li>• Published in English</li> </ul>	<ul style="list-style-type: none"> <li>• All other publications</li> <li>• Studies which did not satisfy the quality standards as determined by the CASP qualitative checklist.</li> <li>• All other languages</li> </ul>
Research type	<ul style="list-style-type: none"> <li>• Qualitative research</li> <li>• Primary research studies</li> <li>• Peer reviewed journal</li> </ul>	<ul style="list-style-type: none"> <li>• All other publications</li> </ul>

Included articles would be published any time up until the date of the search in January 2020.

### Search strategy

It was anticipated that articles of interest may have been published in journals pertaining to nursing, allied health and healthcare, therefore a search of the following databases was conducted using the terms in Table 2.

- CINAHL
- PsycINFO
- MEDLINE
- Web of Science

Further articles of interest were identified by reviewing reference lists and manually searching major journals.

Table 2.

*Terms used in search of subject databases*

<b>SPIDER component</b>	<b>Search terms</b>
Sample	('palliative' OR 'end of life' OR 'terminal care' ti.) AND ('health care professionals' OR 'health care staff' OR 'health care workers' OR 'nurs*' OR 'doctor*' OR 'physician*' af.)
Phenomena of interest	'experience*' ti.
Design	Not specified in search
Evaluation	Not specified in search
Research type	'qualitative' OR 'qualitative research' af.

*Note.* Terms were 'exploded' to include related terms

The process of identifying included articles is illustrated in Figure 1.

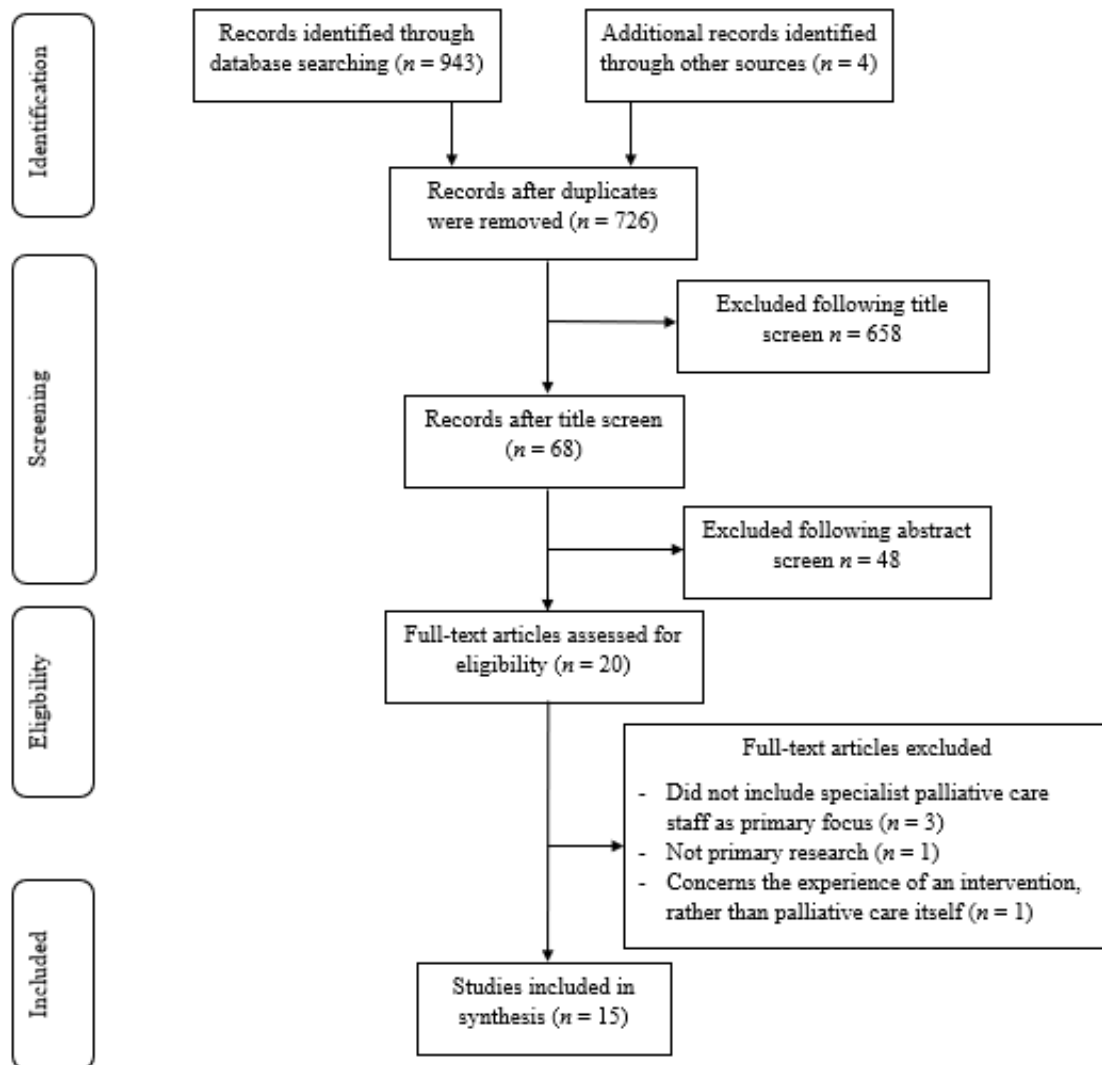


Figure 1. A flow diagram illustrating the different phases of the systematic search process, adapted from “Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement” by D. Moher, A. Liberati, J. Tetzlaff, D. Altman, and The PRISMA Group, 2009, *BMJ*, p. 332-336.

## Literature review

### Studies identified

Fifteen studies were identified and are briefly described below, in terms of their aims.

Key features have also been listed in the table in Appendix A.

Table 3.

#### *Brief description of the fifteen identified studies*

<b>Study number</b>	<b>Authors (date of publication)</b>	<b>Brief description</b>
1	Arrieira, Thofehrn, Porto, Moura, Martins, and Jacondino (2018)	Explored the spiritual dimension that tends to emerge in the end-of-life process with the aim of understanding the experience of spirituality in the daily routine of a palliative care interdisciplinary team.
2	Benoot, Enzlin, Peremans, and Bilsen (2018)	Aimed to explore palliative care nurses' attitudes, roles and experiences with regard to addressing sexual issues in their daily practice.
3	Brajtman, Higuchi, and McPherson (2006)	Investigated the experiences of palliative care unit and palliative home care nurses caring for patients with terminal delirium with a view to develop supportive interventions that enhance the ability of nurses to care effectively for patients and their families.
4	François, Lobb, Barclay, and Forbat (2017)	Aimed to understand staff and relatives' perspectives on the characteristics of conflict and serious disagreement in adult palliative care, including triggers, risk factors and the impact on themselves and clinical care.
5	Green, Jerzmanowska, Green, and Lobb (2018)	Aimed to elicit the experiences of palliative care health professionals when providing care for patients from culturally and linguistically diverse backgrounds which differ from language and culture of the care provider.
6	Johnson, Singer, Masso, Sellars, and Silvester (2015)	Aimed to explore service providers' perceptions and experiences of advance care planning and the use of advance care plans in Australian palliative care services.
7	Mishelmovich, Arber, and Odelius (2016)	Aimed to explore specialist cancer and palliative care nurses experience of delivering significant news to patients with advanced cancer.
8	Muggleton, Guy, and Howard (2014)	In recognition of the ubiquity of disgust in palliative care, the authors investigated how palliative healthcare professionals experience and cope with disgust in their work, and how they are supported in doing so.
9	Parola, Coelho, Sandgren, Fernandes, and Apóstolo (2018)	Aimed to explore and describe the lived experiences of nurses caring in a palliative care unit

10	Penz, and Duggleby (2011)	Aimed to explore the hope experience of palliative care nurses by capturing their hope experience, developing a reflexive understanding of the processes of their hope, and then by constructing a substantive theory of hope of palliative care nurses.
11	Rietjens, Hauser, van der Heide, and Emanuel (2007)	Explored nurses' attitudes and experiences with palliative sedation in recognition of the fact that whilst nurses often participate in its use, little is known about their experiences of it.
12	Treggalles, and Lowrie (2018)	Explored the lived experiences of professional grief among occupational therapists working in palliative care settings.
13	Udo, Lövgren, Lundquist, and Axelsson (2017)	Aimed to explore palliative home care physicians' experiences regarding communicating with patients about their transition from early palliative care phase to the late phase where death is imminent.
14	Vachon, Fillion, and Achille (2012)	Aimed to better understand how palliative care nurses handle death proximity or finiteness in their personal lives. They also sought to understand the subjective spiritual-existential experience in their personal and professional lives; and to explore the possible links between these experiences.
15	Zambrano, Chur-Hansen, and Crawford (2013)	Aimed to explore the experiences, coping mechanisms, and impact of death and dying on palliative medicine specialists when dealing with their patients at the end of life.

### Participants and settings

Studies were selected on the basis that they included palliative care team staff as the primary focus of study and each of the studies satisfied this criterion, however there was some variation amongst the studies.

One noted variation was that the different locations in which the research was conducted contributed to inevitable differences in service provision, ranging from home and community care, to inpatient care. Five studies were conducted in Australia (François, Lobb, Barclay & Forbat, 2017; Green, Jerzmanowska, Green & Lobb, 2018; Johnson, Singer, Masso, Sellars & Silvester, 2015; Treggalles & Lowrie, 2018; Zambrano, Chur-Hansen & Crawford, 2013), three in Canada (François, Lobb, Barclay & Forbat, 2017; Penz & Duggleby, 2011; Vachon, Fillion & Achille, 2012), two in the United Kingdom (Mishelmovich, Arber & Odelius, 2016; Muggleton, Guy & Howard, 2014), with each of the

remaining studies conducted in Brazil (Arrieira, Thofehrn, Porto, Moura, Martins & Jacondino, 2018), Belgium (Benoot, Enzlin, Peremans & Bilsen, 2018), Portugal (Parola, Coelho, Sandgren, Fernandes & Apóstolo, 2018), and Sweden (Udo, Lövgren, Lundquist & Axelsson, 2017), respectively. One study (Rietjens, Hauser, van der Heide & Emanuel, 2007) did not explicitly state where it had been conducted, and all were reported in English.

Palliative care is an internationally recognised field of healthcare which universally attends to the care needs of patients where the focus is not curative. The common element that this review is interested in is that participants are dedicated palliative care staff, regardless of point of delivery.

Another variation is that some studies included oncology professionals (Arrieira, Thofehrn, Porto, Moura, Martins & Jacondino, 2018; Mishelovich, Arber & Odelius, 2016; Vachon, Fillion & Achille, 2012), medical intensive care unit professionals (Rietjens, Hauser, van der Heide & Emanuel, 2007), and patient relatives (François, Lobb, Barclay & Forbat, 2017) in *addition* to palliative care staff. These studies were included in the review as the primary (or at least equal) focus was on palliative care staff. For the purposes of this present synthesis, the study which included patient relatives (François, Lobb, Barclay & Forbat, 2017) was carefully analysed to remove any quote or reference point which did not capture the *staff* experience.

### **Quality appraisal**

The Critical Appraisal Skills Programme qualitative checklist (CASP) UK (2018) was selected as an appraisal tool which was designed to aid in systematic review of qualitative literature. The tool asks questions which fall within three broad domains in order to allow for ready comparison of quality across identified studies. Those domains are: Are the results



valid; what are the results, and will the results help locally (how valuable is the research)? A summary checklist of quality appraisal can be found in Appendix B.

The studies identified were generally strong in methodological quality. All 15 were appraised to have clearly stated their aims, and also to have appropriately chosen a qualitative method to answer the research aims. However, the specific research design chosen to address the aims of the research were not so consistently strong with three studies only partially satisfying this criterion (Brajtman, Higuchi & McPherson, 2006; Johnson, Singer, Masso, Sellars & Silvester, 2015; Zambrano, Chur-Hansen & Crawford, 2013). Each of these studies took a thematic analysis approach, though to capture a depth or richness of data which would better satisfy the questions of individual experiences, they would have been better suited to an alternative, less broad, design. Thematic analysis itself is not considered problematic for this review and for the purposes of capturing experience of participants, and study by Benoot, Enzlin, Peremans, and Bilsen (2018) also used thematic analysis, though its aim was better suited to this approach.

The recruitment and data collection strategy were also felt to be strong consistently across each of the studies, with the exception of the Johnson, Singer, Masso, Sellars, and Silvester (2015) study which was deemed to have not satisfied the recruitment criterion, and partially met the data collection criterion. The authors distributed online surveys with open-ended questions to be completed by health professionals nominated by service directors. Again, this approach itself is not necessarily problematic, though for the purposes of the current review which favours depth of inquiry, online questionnaires did not allow for probing or follow-up questions that direct contact would allow, as was done across all other studies. Most studies used purposive sampling, reflective of the aims of the study, however this naturally has limitations for representation and participant characteristics. Nevertheless,

qualitative inquiry is typically interested in particular groups within particular contexts and as such this was not considered to hinder the quality of the reviewed research.

The relationship between researcher and participants was not always reported clearly whilst others only partially clarified the relationship between researcher and participant. That said, many studies declared no conflict of interests and this was deemed to infer that each of the studies had adequately considered this potential confounding variable. Furthermore, ethical issues had been clearly addressed across most of the selected studies, with the exception of Vachon, Fillion, and Achille (2012) which did not explicitly state, though it did receive 'IRB approval' which monitors healthcare research involving human participants.

Rigor of analysis was sufficient for fourteen of the fifteen identified studies, with the remaining study partially satisfying the criterion. Mishelmovich, Arber, and Odelius (2016) did not explicitly state their data analysis process; who conducted the analysis, whether this was checked by another of the authors or validated by the participants. Most studies outline the steps taken, with most giving samples of verbatim text to demonstrate how data coding translated into themes. Mishelmovich, Arber, and Odelius (2016) did use quotes throughout the results reporting to support the themes and did so to good effect, however might have benefitted from greater transparency with the overall process.

Most studies clearly stated their findings; however, several did not offer any recommendations or implications for practice (Arrieira, Thofehn, Porto, Moura, Martins & Jacondino, 2018; Mishelmovich, Arber & Odelius, 2016; Parola, Coelho, Sandgren, Fernandes & Apóstolo, 2018; Zambrano, Chur-Hansen & Crawford, 2013). Qualitative research often situates itself specifically within the context in which it was conducted, so caution with application of findings is consistent with the methodology, however some reflections or direction for local use could have been better utilised by these studies.

The quality review process has found that most identified studies are of sufficient quality and rigor for inclusion in the current review, with one exception. The Johnson, Singer, Masso, Sellars, and Silvester (2015) study was appraised to have key methodological issues in terms of its approach, participant recruitment and data collection, deeming it less suitable for the present review which is concerned with participant experiences, where depth and richness of data is of primary importance.

### **Synthesis of findings**

In order to answer the review question “what can be learned about the experience of working in palliative care” a thematic synthesis was conducted following the method described by Thomas and Harden (2008), an approach to systematic review aims to bring together and integrate findings of multiple qualitative studies.

Thomas and Harden outline a stepwise process made of three key stages which were followed in the present review. The first involves line-by-line coding of the text and to aid this process, all relevant data was imported into NVivo 10 - a qualitative data analysis software - to facilitate coding. After reading and re-reading numerous times, this first stage produced a total of 106 codes. This was followed by the second stage of generating descriptive themes by grouping or separating codes according to similarities and differences, resulting in seven descriptive themes. The first two stages remained ‘close’ to the original texts, directly deriving themes from their content without attempting to apply any additional interpretation. The third stage involved the application of analytical themes, applying a degree of interpretation where the authors ‘go beyond’ the primary studies, generating new interpretive explanations and hypotheses. This third stage resulted in the generation of four broad analytical themes in order to answer the review question, which were: *The personal and the relational experience; The organisational experience; Coping with death*, and;

*Defensive processes.* Thomas and Harden (2008) acknowledged that analytical themes are inevitably shaped by the researcher's own interpretation and experience. In an effort to make this process transparent, the fourth theme, *defensive processes*, explicitly takes insights from a psychodynamic understanding of defences, tentatively identifying and illustrating how such processes may be involved. Other researchers have sought to explicitly combine thematic analysis with psychodynamic observation to useful effect (e.g. Blacker, Kurtz & Goodwin, 2017).

The current review also included an additional stage which involved cross-referencing the analytical themes with the initial 106 codes. The purpose of this step was to ensure that each of the individual papers were represented in each of the themes.

When possible, quotes from the primary studies, or from the study participants themselves have been used to illustrate themes (see Appendix C for further examples).

Studies have been referenced by number throughout this section for economy, according to the numbers assigned in Table 3.

## **The personal and the relational experience**

### **A relational environment**

Participants in all studies reported that developing a relationship with their patients was an important part of their experience in palliative care. Relational qualities such as trust, listening, striving for a shared understanding, attunement, and authenticity were highlighted as being valuable in facilitating a connection to patients, especially when it comes to conducting difficult conversations around death.

*“It's sad, but on the other hand you often get really... meaningful relationships with people but you may not have met before... in this short space of time this, this atmosphere of complete trust can, is often created”*  
(7, page 154)

However, some papers captured from participants the sense that in palliative care, the relational environment can come with challenges. Paper 4 in particular described how difficult conversations between staff and patients might at times be avoided, or if not avoided messages might be delivered with insensitivity. Furthermore, additional variables such as the patient's history were reported to play a key role impacting the ability to use the relationship as a positive resource.

*‘Suboptimal communication about disease progression (including managing pain, and nutrition/hydration) alongside insufficient clarity regarding the level of care provided by the service, create a context where conflict can flourish’* (4, page 9)

### **The personal and professional**

Participants commonly reported how working in palliative care affects them personally. In several studies participants described how certain patient characteristics might resonate more powerfully with them, making the role more challenging.

*“Sometimes it's a little difficult...we have patients who move us more than others, and the younger they are, the harder it is, and if we have children, the harder it is, and if we know the family, which is almost always the case...it is even harder”* (9, page 184)

Participants also acknowledged that the degree of their personal and emotional connection with the patient might vary depending on a number of factors such as the length

of the relationship or level of personal involvement in the case, or indeed the level of identification as mentioned above. These factors can contribute to the development of intense connections and blurred boundaries between staff and patient.

*“The thing that I have to be mindful of my triggers is actually that (in) those cases sometimes I can invest a bit more time and effort” (12, page 4)*

One participant reflected on how nursing their own father in palliative care affected their relationship to care giving. Noticing how the staff seemed unaware of her father as an individual motivated her desire to tune in to her patients’ personality and temperament. Some participants described their caring role as a part of their identity, however study 14 highlighted that, with proximity to death, participants appeared also to be grappling with their own relationship to death.

*“It’s a chance. I experience something, intense, real, and I want to integrate it into my life... I have no choice but to be in real contact with my values and priorities” (14, page 163)*

### **Spirituality and meaning**

Many of the papers reviewed here captured the sense that palliative care brings with it a powerful inclination amongst participants to reflect on spirituality. Whether personally, or on behalf of patients, participants described how spirituality could bring comfort in the dying process. Some participants also reflected on how a lack of spirituality amongst the staff or the patients can present a challenge for them, finding it difficult to comprehend how a non-spiritual other copes with death.

*“Spirituality strengthens me as a person and as a professional... without spirituality, much of what we do would have no meaning... it enriches us a lot as professionals and greatly enhances the care”*(1, page 3)

Similarly, proximity to death appeared to generate questions about meaning of life and one’s role. Study 14, which asked questions specifically pertaining to spiritual-existential experience, found that some participants felt that their role gave their life meaning, whereas others described being confronted by loss of meaning.

*“I used to pray. It used to reassure me. But now, I am alone doing it and it doesn’t make sense”* (14, page 167)

## **The organisational experience**

### **The nature of the work**

A significant feature of the experience for participants working in palliative care is helping people to ‘die well’, a concept embedded within the culture of palliative care (Ashby, 2017). Participants reported the satisfaction that they experience when feeling that they were able to do this, but also challenges given that dying ‘well’ may not be a reality for many patients.

*“There’s a lot of challenges but... to feel like you’ve negotiated those challenges and that they’re feeling more comfortable, that’s a very satisfying feeling”* (5, page 6)

Participants differentiated their role in palliative care from other forms of nursing, and described the importance of attending to the whole person. Some descriptions from participants emphasised the special nature of the work that they do.

*'Being a palliative care specialist was considered as an opportunity to know patients and to be present in a way that no other medical specialty or health profession could'* (15, page 311)

However, a clear feature of the experience in palliative care involved the uncertainties, high demands, and consequent ethical dilemmas surrounding the dying process and how this can generate anxiety for staff.

*"I remember having questions about – because it was all new to me – what was an appropriate intervention? Was this euthanasia? Was this physician-assisted suicide? Was I being asked to actually kill a human being?"* (11, page 647)

### **Organisational process**

Another clear element to the organisational experience was the way that processes might serve to dictate the dying process for patients. Participants described how there appeared to be a disconnect at times between what is deemed medically necessary, versus the wishes of the patient or their family, or similarly tension arising from the belief that patients need to see things from the staff perspective. This issue appeared to generate some tension for participants, who otherwise operate in a context which emphasises attending to the whole person.

*'The disjuncture between relatives wishing to give the patient food/fluids contrasted with clinician prioritisation of the potential risks of aspiration or choking... "Hydration is a big thing and that ties back to ... level of expectation of the loved ones and really having being told what is happening"'* (4, page 7)



When describing the perceived limits of their role in palliative care, participants were able to use the organisation as a ‘vessel’ into which some of their anxiety could be placed. Highlighting factors such as a lack of training, or simply ‘the way things are’ were some of the means by which this could be achieved.

*“The possibilities are often very limited. We don’t have the opportunity to intervene... usually all we can do is limit the damage. By looking after them as well as possible. That is palliative care” (2, page 1591)*

However, the organisation, and teamwork in particular, were acknowledged to be a key resource for staff, enabling them to continue good work and also to act as a source of support.

*“There are always situations that raise doubts in me and that I sometimes cannot solve by myself, and I turn to the team. And there are things that are sometimes hard to accept; we need to speak to each other” (9, page 184)*

## **Coping with death**

### **Coping in a palliative care context**

The powerful emotional nature of the palliative care experience led participants to acknowledge the important ways in which they adjust in order to cope, but also how they sometimes feel that they are not coping. Feelings such as anguish, anger, loss, helplessness and guilt were amongst the feelings that were mentioned as features of working in this context.

*“There have been situations that, unfortunately, were not so peaceful, and then yes, we go home, and we are disturbed by them... but there you go! We*

*have given everything, we have done everything, but it is not having an effect... then it becomes a moment of anguish” (15, page 313)*

Participants also acknowledged that working in palliative care has enabled them to develop and strengthen their resilience. Their sense of reward came in noticing the way that their work helps them to feel valued and validated, and generates respect amongst their colleagues, as well as in giving them a professional presence in the community.

Another noted feature of ‘coping’ was in participants’ reframing of their experiences; highlighting positive meaning whilst playing-down the negative impact of dealing with death and dying with such frequency. Whereas others described a process of compartmentalisation which, they felt, enabled them to function across the different areas of their lives, -

*“to me, keeping the positive aspect of hope is important. I think that’s how I do a lot of the definition of hope, is through the optimism, being positive and everything in the negative side kind of brings it down” (10, page 289)*

Understandably, participants felt that witnessing suffering was a particularly difficult part of their role, but this came with the natural opposite admission that the work feels easier to manage when patients were perceived to be ‘coping’ with their prognosis.

### **Confronted by death**

Paper 1 poignantly acknowledged that dying patients serve as a mirror for staff, in which they are able to see something of their own death (page 4) and indeed, throughout the papers identified here, a theme emerged around the notion that for staff, families, and patients, being confronted by death can represent a tremendous personal challenge and contribute to meaningful and sometimes painful reflections on life.

*“There is always a time when we face our own death” (9, page 183)*

And in this challenging space, staff reported a desire to manage patient symptoms, or become preoccupied with a 'good death' in order to manage the emotional pain. In some cases to the extent that doing so may shorten the patient's life.

*"We were treating symptoms that could not be treated in any other way... We did him the better service by getting him comfortable than when we shouldn't have done that at all. Maybe he would have lived a couple of days longer, but then he would have been very uncomfortable"* (11, page 646).

### **Defensive processes**

This theme is more analytical in nature and should be understood as a commentary of possible factors which are involved in the process of delivering and experiencing palliative care. Useful to note here is that in challenging healthcare contexts, such as palliative care, the use of defence mechanisms as a means for an individual mind to protect itself from becoming overwhelmed is both natural and inevitable and does not itself indicate pathology. Psychoanalytic understandings of defences suggest that only if overused or extreme, or compounded by repeated exposures without the opportunity to metabolise and digest painful experiences, can they become problematic (Ballatt, 2011). It is not the aim of this report to comment on the degree, usefulness, nor pathology of any of the defensive processes described.

These processes were observed to span across all themes, but were also felt to represent a unique category as described below.

Table 4

*Description of psychodynamic defence mechanisms*

<b>Psychodynamic defence mechanisms</b>	<b>Description</b>
Denial	Refers to the obliteration of perceived threat, in the mind.
Reaction formation	Anxiety provoking or unacceptable emotions and impulses are mastered by exaggeration of the directly opposing tendency.
Omnipotence	Involves the illusion of unlimited power, with no awareness that others have a separate locus of control.
Rationalisation	Leads us to invent reasons for our feelings and behaviour which are more comfortable to us than the real ones.
Splitting and projection	Where feelings and thoughts that are contradictory and uncomfortable cannot be contained or tolerated and are 'split' and 'projected' (located) into another. The concept originates from the work of Melanie Klein.
Projective identification	Involves attributing states of mind to another person and relating to that other person as if they embodied the projection. The interactional force of this dynamic can result in the recipient acting in a manner congruent with the projection.

*Note.* Defence mechanisms and descriptions taken from Lemma (2003, p211) and Ballatt (2011, p56). This is not an exhaustive list, but rather a summary of defences described by this report.

**Denial**

Speck (1994) suggested that one of the unconscious attractions of working with the dying is that the role can serve to maintain the fantasy that death only happens to others. This review found numerous possible examples of this defensive structure operating amongst participants.

*"I think of myself as being lucky to be a... nurse, even after 10 years. You know, when we spend time with patients, sometimes they thank us. Well, I always feel I am the one who should thank them most . . . because I experience something I couldn't have if they had not existed . . . even if it is in suffering . . . My work makes me grow and my patients bring me peace. What more do you want?!"* (14, page 158)

The quote illustrated here may also represent something which Freud (1917) described as a ‘manic triumph’, when the mind realises that *it* is not the one dying. This position often brings with it a sense of guilt, which can be circumnavigated when a patient offers gratitude:

*“There’s a lot of challenges but I have to say it’s lovely to think that you can give people from a different background a good experience going into a death ... and to feel like you’ve negotiated those challenges and that they’re feeling more comfortable, that’s a very satisfying feeling”* (5, page 6)

However patients were not always felt to be appreciative, and in one participant’s description it appeared that the patient was held responsible for not being able to accept the support being offered:

*“I had a patient; he didn’t even want to talk about it. I tired of asking him... He didn’t want anything. Some of them also refuse to see it, to accept it. They are totally blocked. I try to get them prepared so we can intervene, but it’s like there is nothing to do with them”* (14, page 167)

### **Reaction formation**

Where denial alone may not be enough to quell the guilt experienced by staff, reaction formation goes further and the individual (or indeed the culture) makes conscious efforts to act in ways directly opposite to the impulse which is not felt to be acceptable. For example staff may become self-punitive, and this may drive them to offer more and more of themselves (Langs, 1997). Throughout the studies reviewed here were several possible examples of this defence mechanism at work.

*'They often expressed a feeling of not doing enough and aimed at totally and completely relieving patients' pain, which was not possible most of the time. Therefore, they seemed to be caught in a dynamic in which they gave more than they were able to benefit from their caring interactions.'* (14, page 168)

## **Omnipotence**

Another potential defensive process observed was in the subtle and not-so-subtle ways that staff position themselves as if able to alleviate all suffering, or provide a 'good death' even where this may never be possible:

*"... we all know the right ways of doing things, warning shots, and giving information and not lying to people, but I think sometimes not completely destroying all hope for them."* (7, page 156)

In paper 11, aggressive treatment approaches were seen as a way to alleviate the physical suffering of patients, but also the emotional suffering of families, even when this was acknowledged to potentially hasten death.

*"Well initially it was for the patient's comfort but then... I sure felt that he was comfortable and then secondarily it was for his wife's comfort. To make sure that she knew that we'd give him enough sedation to make him comfortable"* (11, page 646)

*'Shortening of life was acceptable because palliative sedation was the only way to address suffering'* (11, page 646)

One participant described how she now chooses her words more carefully lest they might cause the patient to die. Highlighting the vulnerability of such a defensive structure, that when the mind thinks itself omnipotent as a defence *against* death, so too it is powerful enough to cause it.

*“I can still see her face. She said to me um, do you think I'm dying. And it was such a frank question... I said to her yes I think you are and she promptly dies that night and I can remember thinking to myself, oh gosh was I too brutal? You know... so I reflected on that and now, when someone asks me, “do you think I'm dying?” ... I wouldn't give that answer generally” (7, page 157)*

### **Rationalisation**

Speck (1994) suggests that when working with dying people, a way to avoid the difficulty of talking about death is to rationalise or create a distance from it. Throughout the papers reviewed here there were several examples of staff using language to distance themselves from the painful reality of a person facing the end of their life.

*“The term supportive care, I find that's actually really useful to make inroads with family, because often it's about selling a service, so it's almost like a marketing tool, I mean rather than talking about palliative care you talk about supportive care, and it actually works quite well” (5, page 4)*

### **Splitting and projection**

One of the key insights of psychodynamics is that where intense feelings are found, these can exist in oppositional tensions. Polarised feelings of love and hate, or ‘good’ and ‘bad’ can be separated in the mind and unwanted feelings placed in the other (Ashby, 2017; Klein, 2002). Palliative care can be particularly affected by such splits, where culture propagates a fantasy that care for the dying is undertaken by dedicated, caring, and wholly nice people – protecting everyone from facing the fact that care for the dying can arouse feelings which are also disturbingly not-nice (Speck, 1994).

*“to me keeping the positive aspect of hope is important. I think that’s how I do a lot of the definition of hope, is through the optimism, being positive and everything in the negative side kind brings it down.” (10, page 289)*

However, when negative feelings are disavowed, they have to go somewhere (Ashby, 2017) and in some instances staff experienced the family as the source of the problem. In this case, a patient becoming unsettled could only be understood as the result of the family’s presence.

*“But then families are also the hardest part because they come in with all their love at all hours of the day and night, and it can unsettle them a little bit... it seems like they become unsettled when the family come” (5, page 7)*

### **Projective identification**

The studies included in this review also yielded examples of potential projective identification, a process where the *recipient* of a projection experiences something of the feeling as their own (Klein, 2002). In this example, the nurse describes an interaction with her husband where the painful reaction to death is his alone, such that he feels he cannot bear it.

*‘For instance, [name] discussed sharing experiences of death and dying with her partner and how this affected him: “... after a period of time he just said: ‘that is so sad, it makes me feel really, really sad every time you tell me... I can’t cope with it’”’ (12, page 5)*

### **Discussion and limitations**

The present study aimed to critically review the qualitative literature surrounding the experience of staff working in palliative care with a view to answering the question ‘what can be learned about the experience of working in palliative care’. Palliative care is a specialty of



health provision which explicitly aims to offer care which is not singularly focussed on medical concerns, but also psychological, social, and spiritual needs. In the studies reviewed, participants reported a ubiquitous sense that the experience of working in palliative care is not just a professional one, but is also deeply personal. There was a sense that in providing care which reaches across domains, staff tend to give more of themselves in order to satisfy the cultural and internal expectations surrounding care for the dying (Ashby, 2017; Kristjanson, McPhee, Pickstock, Wilson, Oldham, & Martin, 2001).

However in giving more, so too does the role feel as if it *takes* more from them, and emerging from the papers reviewed here was some indication of the pressure on staff to provide a good death even where this may not be possible. Recent research highlights the problem that there is not a shared or clear concept of what a ‘good death’ is (Krikorian, Maldonado, & Pastrana, 2020). Furthermore, staff reported difficulty in separating their personal and professional lives, with some expressing significant distress – particularly when patient characteristics resonate with their personal lives in some way. What was found to be missing from the papers reviewed here was any exploration of how these pressures or difficulties might affect the delivery and quality of care. A study examining the variables which impact quality of care found that communication was a key element which leaves patients, families, and care providers with a sense that good care had been provided (Seccareccia et al., 2015), however the personal/professional interaction remains unexplored.

Frequent contact with death and dying was understandably experienced by staff as troubling and difficult. However there appeared to be a shared sense that with time spent in the role there is a development of a resilience which allows them to survive the work and also to perform their duties well. This experience was not unanimous however, and some participants communicated something of their existential distress, leading them to question the value and meaning of their lives. The qualitative nature of the studies reported here means

that it is not possible to capture data about participant differences which might help to better understand where the crucial differences lie between those who develop ‘resilience’, and those who feel that they do not. That said, it may be that individual differences are the key to understanding how some experience themselves as ‘resilient’ whereas another do not. The studies reviewed did not capture data which might offer insights into these individual differences. Furthermore, whilst appraised to be of a quality suitable for inclusion, several of the studies included in this review used methodologies which are less ideally suited to exploring the lived-experience of staff in a way which captures a consistent level of depth and nuance. It was felt that the methodological differences amongst the papers included led to differences in the *affective* quality of the content extracted from them.

Another limitation of this review is in its unique use of the term ‘experience’ as a search criterion. Whilst this word was chosen intentionally to capture studies which focus on the lived and emotionally-felt phenomena in the context of palliative care (which the word ‘experience’ usefully summarises), indeed there will inevitably be some semantic overlap with other similar words which could have been used to search the literature. This study focussed on the term ‘experience’ as a way of filtering the search and to define and operationalise the search process according to the parameters described above, but with the consequence that there may remain studies relevant to the present review question which were unexplored as a result.

During the search process it also became apparent that there are many papers published which capture something of the experiences of end-of-life care in its many facets. Examples were found to include a variety of different kinds of staff offering end-of-life care in a variety of care settings (e.g. intensive care unit (ICU)). Furthermore, many papers were noted that captured the experiences of patients, caregivers, and families; each potentially offering something valuable for future review.

Finally, it is evident from the current review that palliative care is a specialism in which staff will experience a powerful and affecting interpersonal milieu. Dying patients, their families, organisational pressures, ones own internal world and the collision between the personal and the professional impact staff on a daily basis. This review remained close to the data throughout, representing as accurately as possible the findings of the papers included with the aim of understanding the experience of staff. However, this review also offers a psychodynamic interpretation on the analysis, tentatively illustrating the possibility of unconscious and/or defensive processes which may be operating for those participants involved. It has been acknowledged that palliative care is a context where powerful unconscious processes will be operating; inevitably impacting the individual and the organisation (Ashby, 2017; Katz & Genevay, 2002; Menzies, 1960), and indeed the results described here may support this view. However, the psychodynamic interpretations outlined are limited by the lack of direct contact with participants and/or services, and should be regarded accordingly. Perhaps most helpfully understood as *possibilities* which may facilitate thinking for those working in palliative care services, or indeed motivation for future research to explicitly explore unconscious processes and their effects on the experience of staff.

It is evident from the findings that the challenges of working in palliative care are numerous, though there is a space within the qualitative literature to understand and explore the more *interpersonal* challenges experienced by staff. Specifically, what they are and how they might be defined from the staff perspective, to gain an in-depth understanding of what it is like to experience such challenges, and to consider on the basis of these understandings what might be the most helpful to meaningfully support those staff.

## **Implications**

### **Clinical implications**

The findings of this review offer some useful implications for clinical practice; particularly in the domain of staff support and space for reflection.

Whilst the personal and relational context of palliative care can make the work powerfully meaningful for staff, so too can it become an environment where staff are vulnerable to avoiding difficult conversations with patients. Or, where not avoided, the desire to contain challenging emotional responses from patients can lead to messages being delivered with insensitivity. This review also found that professionals can be particularly affected by numerous variables such as resonant patient characteristics, length of involvement, or personal circumstances. Such variables can lead to a blurring of professional boundaries, and deficits in care quality. Services should thus pay attention to the support structures around professionals working in these highly emotive conditions, taking time to notice the discreet ways that individuals might be affected.

Narratives around ‘dying well’ can generate friction for staff, particularly given that may not always be possible (Krikorian, Maldonado, & Pastrana, 2020). Linked with this is the propensity to use palliative sedation to ease symptoms which are distressing for patients, families, and staff (Rietjens, Hauser, van der Heide, & Emanuel, 2007). Some staff in this review reported feeling that this raised ethical concerns and fears that somehow they might be somehow euthanizing patients. Professionals may wish to consider the extent to which they feel trained in the ethics and practice of administering sedative interventions for dying patients – seeking support where issues arise. Whilst services may benefit from considering/reviewing their training programs with the aim of ensuring they support the

nuanced, sensitive, and flexible administration of sedative or pain medication (Twycross, 2019).

This review also tentatively explored the potential for unconscious variables which may have a role in the experience of palliative care professionals, and identified some of the psychological defences which may be operating in such a context. Defensive structures, both individual and organisational, are most usefully thought about on an individual basis and in a way which takes careful account of the context (Kvale, 2004). This review is not able to offer such an examination, however it does demonstrate the plausibility of unconscious influences in the experience of palliative care work. Indeed, given its plausibility, services may wish to consider the utility of clinical supervision which can give space to the exploration of such factors given that, if true, the implications can be significant and may affect staff wellbeing and care delivery (Ashby, 2017).

### **Research implications**

The following suggestions are made for researchers wishing to contribute to the literature in this area.

- Mixed-methods studies which report quantitative data alongside qualitative to explore categorical differences between participants. This may offer unique insights into differences between participants who see themselves as resilient and those who do not
- In-depth exploration of how interpersonal challenge is understood, experienced, and defined by staff working in the context of palliative care.
- Qualitative research to understand the staff perspective on how the personal and professional overlap in the work setting and how this affects quality of care provided.

- Systematic literature review of the wider qualitative literature including that which concerns professionals working in different end-of-life contexts, as this may offer further valuable contributions to understanding the experiences of working with people who are dying.

## **Conclusions**

In conclusion, this review synthesised qualitative findings of existing literature from 14 papers, offering a comprehensive understanding of the experiences of health care professionals working in a palliative care context. This review also explored unconscious factors which may be involved in the process of delivering and experiencing palliative care, from a psychodynamic theoretical perspective. In particular, illustrating how defensive strategies may be indicated in the content of the papers reviewed.

Palliative care staff were found to engage in their work in a way which focussed on the relationships that they develop with patients, giving particular priority and value to the fostering of authenticity and attunement to the needs of their patients. However the context was also found to be deeply affecting on a personal level, and there appeared to be a shared sense that certain patients characteristics, or personal life variables, made the work more challenging. Some staff also reported existential and spiritual concerns, and the review found that the context of caring for the dying could confront staff with difficult questions around their own mortality and quality of life. That said, this very context could also generate fervour for life that other healthcare settings may not.

Organisational pressures were found to be a challenge for staff, particularly around decision making and communication issues, however the organisation also served as a helpful

vessel into which staff could place their frustrations or anxieties. Staff reported feeling that their colleagues were an important support structure.

Whilst unconscious influences are inevitable with such affecting work, it is possible that with the level of complexity involved in providing palliative care, staff and patients may benefit from careful and thoughtful attention to such variables. It is therefore paramount that appropriate training and supervision is offered, in order that staff can feel confident and equipped to safely carry out their work and that individuals experiencing personal or interpersonal distress can be supported.

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KYLE BOYD BSc (Hons.)

**MAJOR RESEARCH PROJECT**

**SECTION B: EMPIRICAL PAPER**

**Palliative care nurses' experience of interpersonal challenges with dying patients: An interpretative phenomenological analysis and psychodynamic exploration.**

WORD COUNT: 7,997 (+485)

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church

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SALOMONS INSTITUTE

CANTERBURY CHRIST CHURCH UNIVERSITY



## Abstract

**Background:** The extant literature highlights comprehensively the extent to which palliative care is a challenging environment for staff, and it seems evident that there have been concerted efforts to mediate these challenges in order to support staff and patients. However, to our knowledge there is no research which has explicitly sought to explore how the unique interpersonal milieu is experienced by staff; in particular with reference to interpersonal challenges

**Methods:** Semi-structured interviews were held with seven palliative care nurses. Data were analysed using Interpretative Phenomenological Analysis (IPA), and psychodynamic exploration.

**Results:** Three master themes emerged from the data were: The personal and emotional experience; feeling responsible, or feels as if what I have to offer is not enough and, where my support comes from.

**Conclusions:** Findings highlighted that interpersonal challenges were experienced by palliative care nurses as emotionally difficult and painful. Nurses shared their complex experience of responsibility over the difficulties faced by patients as they approach death, and for some this sense of responsibility contributed further to feelings of failure. Participants commonly reported that the support of their colleagues was sustaining, though it emerged that the absence of clinical supervision puts staff and patients at risk. Future research may explore the relative experiences of other palliative care health professionals. A role for psychodynamically-informed supervision is suggested as one intervention.

**Keywords:** palliative care, interpersonal challenge, psychodynamics

## **Introduction**

### **Anxiety**

Anxiety is a universal human experience, and according to the Tavistock Institute's tradition, it is one of the psychodynamic 'facts of life' (Ashby, 2017). Anxiety is described, at least in part, as a response to a threat to one's psyche which psychological defences have not adequately negotiated (Clemens, 2003; Cramer, 2000). Therein inferring that defences might typically maintain an unawareness of things which would be intolerable to the conscious experience; that is until some subjective threshold had been reached rendering these defences less effective (Timmermann, Naziri, & Etienne, 2009). The notion of unconscious defensive processes has received empirical support across a range of psychological theoretical frameworks (as described and summarised by Cramer (2000)). Cramer goes on to suggest that many such examples are simply relabelled processes previously described by psychodynamics (pp. 639), but in the least can be understood as convergent evidence for the processes described in this report. Empirical evidence supporting the presence of defensive processes has been found in studies looking at a child's defensive response to separation from a primary caregiver (as summarised by Cassidy and Kobak (1988)); emotional responsivity in child development (Chisholm & Strayer, 1997); threat to individual identity (Grzegolowska-Klarkowska & Klarkowski, 1990) and, in the context of abuse and neglect (Fonagy, Steele, & Steele, 1991).

According to psychodynamic theory, defensive coping for anxiety can contribute to significant interpersonal difficulty if left unaddressed (Jarvis, 2004). Ronald Britton (1992) argued that if experiences cannot be held in the mind (when overwhelming or unbearable), then they are embodied, hallucinated/projected, or enacted (p. 106). If a powerful feeling

such as resentment is projected, for example, then the feeling is displaced onto substitute targets; it is the other who is seen as resentful, ungrateful, or envious, not ourselves.

This has important implications in healthcare contexts where individuals will daily be exposed to painful and anxiety-provoking experiences, and Menzies (1960) studied the ways that social systems such as hospitals are organised as if to serve the function of defending against anxiety. Throughout healthcare systems, she described the mechanisms that seemingly facilitated the collective defence from that which generates anxiety. A contemporary revisiting indicated that much of its original thesis remained relevant and suggested that, given the unconscious (and therefore hidden) nature of defence systems, there is an ongoing need for re-thought, and rediscovery (Lawlor, 2009).

### **Death and palliative care**

Another of the facts of life according to the psychoanalytic tradition concerns the inevitability of death and our struggle with this knowledge (Ashby, 2017). Sigmund Freud (1915) suggested that in the unconscious “every one of us is convinced of his own immortality” (p. 7), showing an unmistakable tendency to put death to one side. Death presents the mind with an absolute and insurmountable anxiety, and with this considered it would be important to study the impact on, and experience of, those individuals (and systems) for whom death cannot be as easily ‘put to one side’. Palliative care is one such setting, and in the face of life-threatening illness, it is natural and understandable for professionals to feel a range of tensions arising from their own powerful and painful experiences, or those of their patients. Straker (2013) recognised the potential that unacknowledged anxiety can have in the context of end-of-life care, both *intrapersonally* and *interpersonally*, and several authors have observed the difficulties that can arise and the tremendous affect that can be experienced in relationship with dying patients in the context of

palliative care (e.g. Giamportone, 2015; Jones, 2003; Katz & Johnson, 2016; Muggleton, Guy, & Howard, 2014; Owens, 2007). Straker suggests that unacknowledged anxiety might in fact be responsible for a great proportion of challenging interactions in this context, can give rise to powerful defensive processes, and also that it can contribute to deficits in care delivery (p. 6), highlighting the importance and value of making the relational domain of palliative care an area for study (as suggested by Ashby, 2017, p210-211).

### **The experience of palliative care**

In recognising the complexity of working in palliative care, many researchers have sought to understand the impact on staff. Centring on constructs such as coping and resilience (e.g. Gillman et al., 2015), and staff burnout (e.g. Swetz, Harrington, Matsuyama, Shanafelt, & Lyckholm, 2009; Martins Pereira, Fonseca, & Sofia Carvalho, 2011), empirical research and review studies have been able to contribute to the development and assessment of interventions aimed at supporting staff and protecting against such difficulties. However, it has been acknowledged that factors affecting staff are often idiosyncratic, subtle, and complex (Martins Pereira, Fonseca, & Sofia Carvalho, 2011), and as described above the relationship between patient and staff are of crucial importance given the powerful and affecting nature of palliative care (Straker, 2013; Katz & Johnson, 2016). Indeed, these variables are not easily captured when examined through the lens of the constructs highlighted here.

A number of researchers have sought to focus qualitatively on the experiences of staff in order to capture this subtlety of experience. In one study Parola, Coelho, Sandgren, Fernandes, and Apóstolo (2018) highlighted that when caring in palliative care, nurses are living an experience that focuses on the relationship with the other. A resounding feature of the experience captured by this study however, was concerning the exhaustion of staff.

Previous research has revealed that burnout levels in palliative care is lower than in other settings (Parola, Coelho, Cardoso, Sandgren, & Apóstolo, 2017), demonstrating the complexity of nursing practice and the need to further understand where the challenges lie.

Seed and Walton (2012) conducted a grounded theory study to answer the question of what challenges staff face in palliative care, however the findings centred on the individual and ways of coping, rather than the *relational* and what it is like to *experience* those challenges. Further experience-focussed research has captured powerful and moving accounts of the staff relationship with patients, such as how staff experience patients with disgusting symptoms (Muggleton, Guy, & Howard, 2014), conflict in palliative care (François, Lobb, Barclay, & Forbat, 2017), and breaking difficult news (Mishelmovich, Arber, & Odelius, 2016), each offering a window through which one can gain some understanding of how interpersonally challenging palliative care can be.

### **Rationale for the research**

Consistently the experience-based literature reveals that the experience of staff working in palliative care is fraught with intense challenges; challenges that confront staff with conflict, ethical dilemmas, existential pain, and organisational pressures. And in this context, when also facing potentially overwhelming interpersonal interactions with patients and family, fuelled by anxieties associated with death and dying, there lies the potential for compromises in care delivery if left unacknowledged (Rosenstein & Park, 2018; Strous, Ulman, & Kotler, 2006; Timmermann, Naziri, & Etienne, 2009).

The extant literature highlights comprehensively the extent to which palliative care is a challenging environment for staff (usually nurses), and it seems evident that there have been concerted efforts to mediate these challenges in order to support staff and patients.

However, to our knowledge there is no research which has explicitly sought to explore how the unique interpersonal milieu is experienced by staff; in particular with reference to interpersonal challenges. Furthermore, studies linking experience, coping, and defence mechanisms are rare (Timmermann, Naziri, & Etienne, 2009), so psychodynamic insights might have something unique to offer in the context of qualitative palliative care research, as a means to explore possible factors which underlie the challenges described by participants.

### **Aims of research**

To gain an in depth understanding of palliative care nurses' experiences of interpersonal challenges with dying patients.

#### Primary research questions

- a. How do a sample of palliative care nurses experience and make sense of what they perceive to be challenging interactions with dying patients
- b. What is the emotional impact on them

#### Secondary question

- c. To what extent can these experiences together with the emotional responses of palliative care nurses be explained by psychodynamic constructs and theory

### **Method**

#### **Design**

This study used semi-structured interviews to conduct an Interpretative Phenomenological Analysis (IPA), which is concerned with how individuals make sense and meaning of their

experiences and how these experiences take on significance for them (Smith, Flower, & Larkin, 2009). IPA involves a process of careful interpretation, where the researcher makes sense of the participant making sense of their experience. IPA is idiographic insofar as it focuses on the detail and depth of a particular experience for the individual, in a particular context. IPA is a methodology often used in health and clinical psychology contexts, and has been used in previous research to capture the experience of palliative care staff (Muggleton, Guy, & Howard, 2014; Treggalles, & Lowrie, 2018; Vachon, Fillion, & Achille, 2012).

### **Participants**

IPA methodology requires a homogenous sample (Pietkiewicz & Smith, 2014), thus it was initially planned that qualified clinical palliative care staff would be recruited from one NHS Trust, who were working in a single location. The impact of the coronavirus pandemic was widespread within the National Health Service (NHS) and for this project it became impossible to recruit according to these initial plans. As such the recruitment strategy was changed, and information about the project was distributed via two palliative care professionals' networks. The administrators of these networks distributed the project information amongst its members and palliative care nurses were encouraged to contact the researcher directly. It should be noted that all participants were NHS staff, though participation was independent of their NHS affiliation and interviews were conducted in their own time and not on NHS premises.

Seven participants were recruited for the study, slightly exceeding the suggested sample size for IPA (according to Smith, Flower, & Larkin, 2009). Inclusion criteria to take part in the study was being a qualified nurse, currently working in a palliative care setting, and able to speak English at a level sufficient to engage in an interview. All participants were White British, and only one participant was male. All other demographic information is listed

in Table 1. Nurses worked in a variety of palliative care settings including acute inpatient and community roles, based across the United Kingdom.

Table 1.  
*Participant demographic information*

<b>Participant</b>	<b>Role</b>	<b>Age</b>	<b>Years qualified</b>	<b>Years in palliative care</b>
<b>PCN1</b>	Nurse consultant	54	29	15+
<b>PCN2</b>	Nurse consultant	50	30	10
<b>PCN3</b>	Nurse consultant	47	26	18
<b>PCN4</b>	Clinical Nurse Specialist	32	12	1.5
<b>PCN5</b>	Clinical Nurse Specialist	48	28	5
<b>PCN6</b>	Nurse Specialist/ Ward manager	39	17	2
<b>PCN7</b>	Clinical Nurse Specialist	33	6	1

### **Procedure**

An advertisement (Appendix H) was sent out to two palliative care professionals' networks via email which outlined the study and invited interested parties to contact the researcher using the email address provided. Palliative care nurses who expressed an interest were briefed during a telephone call (Appendix I) before being sent a participant information sheet (Appendix J) and consent form (Appendix K) and offered the chance to ask any further questions about participating in the study. Participants who were happy with the project information and were willing to consent, returned their signed consent forms in the post. Interviews were scheduled for a time that suited them and were held online via video conferencing software.

### **Interviews**

The approach to interview was to use a semi-structured schedule which included broad questions and prompts to focus the interview, but with a relative freedom which allows



participants to bring what was important to them (Appendix L). This approach also allowed the researcher the freedom to pursue discussion points organically and according to the direction the participant wishes to go, consistent with IPA methodology. Whilst the interview schedule was focussed on challenges, and thus may have naturally biased responses towards more negative experiences, the interviews themselves broadened to a wider range of challenging experiences.

Interviews were conducted individually using online video conferencing software with end-to-end encryption, which was purchased with a private licence. Interviews were audio recorded using a password protected dictaphone before being uploaded to a secure password protected laptop and transferred to an encrypted memory stick.

Interviews lasted between 42 and 73 minutes. Participants were reminded about the limits of confidentiality and their right to withdraw at any time. Interviews were carried out over a period of two months from August to October 2020. Interviews were transcribed verbatim, capturing semantic content, and any confidential information was anonymised. Once transcribed and anonymised, interviews were kept on a password protected laptop. Transcripts are stored for ten years.

### **Data analysis**

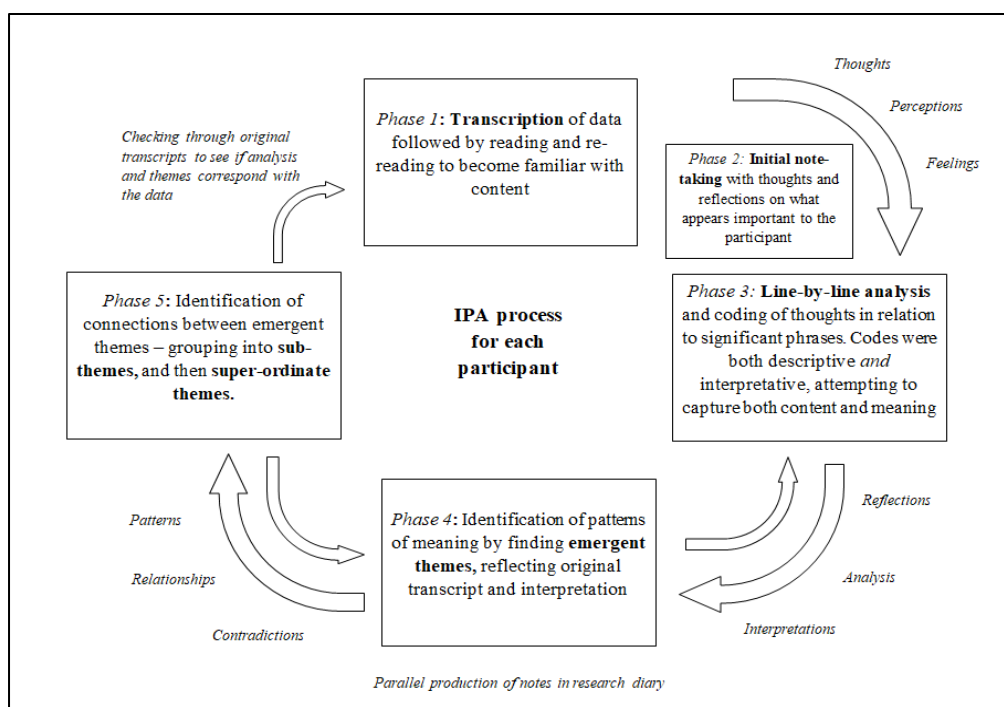
The process of IPA is not prescriptive (Smith, Flower, & Larkin, 2009) however the analysis here was conducted according to a similar trajectory as the one conducted by Dennison (2016) who effectively strategized her analysis to first attend to the data inductively (data-driven), before an additional layer of analysis to attend to theory-based constructs within the data. The first stage of the process involved reading and re-reading the transcripts to become familiar with the data. The second stage involved making initial notes and

highlighting areas of the data which stood out to the researcher (see Appendix N for sample). The third phase was a twofold process wherein the researcher began line-by-line analysis, and thoughts in relation to segments which seemed important for the participants were noted and coded, whilst separately noting tentative interpretations according to psychodynamic constructs (see Table 3 and Appendix P). To facilitate the coding process, all relevant data was imported into NVivo 10 - a qualitative data analysis software. The fourth phase involved noting emergent themes (Appendix O).

Table 2.  
*Description of psychodynamic constructs*

<b>Psychodynamic constructs</b>	<b>Description</b>
<b>Defence</b>	A mental process initiated unconsciously to avoid experiencing conflict or anxiety.
<b>Containment</b>	The ability and capacity of the individual to understand, be attentive to, tolerate, hold and manage emotions
<b>Denial</b>	Refers to the obliteration of perceived threat, in the mind.
<b>Repression</b>	Refers to an unconsciously purposeful forgetting. It is the defensive use of memory.
<b>Reaction formation</b>	Anxiety provoking or unacceptable emotions and impulses are mastered by exaggeration of the directly opposing tendency.
<b>Undoing</b>	Uses designated actions or thoughts to neutralise something that was said or done.
<b>Idealisation</b>	Involves the conviction that another person to whom one can become attached is omnipotent and benevolent.
<b>Omnipotence</b>	Involves the illusion of unlimited power, with no awareness that others have a separate locus of control.
<b>Splitting and projection</b>	Where feelings and thoughts that are contradictory and uncomfortable cannot be contained or tolerated and are 'split' and 'projected' (located) into another. The concept originates from the work of Melanie Klein.
<b>Projective identification</b>	Involves attributing states of mind to another person and relating to that other person as if they embodied the projection. The interactional force of this dynamic can result in the recipient acting in a manner congruent with the projection.
<b>Acting out</b>	Involves discharging into action a disturbing feeling so as to avoid thinking about it.

*Note.* Defence mechanisms and descriptions taken from Lemma (2003, p211) and Ballatt (2011, p56). This is not an exhaustive list, but rather a summary of defences referred to by this report.



*Figure 1.* The IPA process for each participant, based on the process described by Dennison (2016). The boxes represent the five distinct phases of the analysis process, whilst italicised words and directional arrows represent the parallel thinking that aided the overall process of IPA.

This process was repeated for each transcript individually, however the fifth and final stage was to examine themes across participants, grouping together emergent themes, which led to the development of sub-themes (Appendix Q) and super-ordinate themes (Appendix R). The fifth stage represented a shift from examining what was being experienced at an individual level, to what was shared amongst participants (Cooper et al., 2012). The process of analysis was not linear and involved transcripts being continually reviewed. A table was created to document superordinate and sub themes and related quotes from participants (Table 3).

### **Reflexivity and quality assurance**

Yardley's quality appraisal tool (Yardley, 2008) was used as a guide to ensure quality and rigour. Extant literature was carefully examined to facilitate sensitivity to context. In terms of 'coherence and transparency', IPA accepts that suspending all presuppositions when studying a phenomenon is difficult, and so encourages a process of reflexivity to enable assumptions to be foregrounded and actively considered (Fox, Martin & Green, 2007, p. 18). A bracketing interview was carried out with a lead supervisor prior to conducting interviews, allowing the researcher to reflect on some of his own biases, which included the assumption that all palliative care nurses will be in some way defended from the reality of death and that this will negatively affect the care that they provide. In addition, an epistemological positioning statement was produced (Appendix D) and examined by the project supervisor to further explore the position and views held by the researcher prior to completing the interviews. To ensure commitment to methodological rigour, the researcher carefully documented each step of the data collection and analysis process. A number of transcripts and annotations were shared with lead supervisors (Appendix M).

### **Ethical considerations**

Ethical approval was obtained through the Salomons Ethics Committee (Appendix E) and also the Health Research Authority (HRA) (Appendix F). A revised ethics application was submitted and approved by the Salomons Ethics Committee (Appendix G) after the coronavirus pandemic made it impossible to recruit from the NHS site as originally planned. Participants were advised of their right to withdraw from the research at any time without the need to give an explanation; they were also encouraged to contact the researcher if they had any questions following the interview.

## **Results**

The analysis resulted in three superordinate themes, comprised of a total of twelve sub-themes, which are described below. Quotes will be used illustratively throughout the text, but for depth Table 2 provides a description of all themes together with yet more extracts from the interviews to allow for a deeper appreciation of the data. In addition, psychodynamic features observed within the data have been highlighted in Table 3 and will be discussed further throughout the results and discussion sections, respectively.

Table 3.  
Themes and corresponding quotes

Superordinate themes	Sub-themes	Quotes
<b>The personal and emotional experience</b>	About me/ the reason I'm here	<p><i>So that's one of the reasons I came to work in the hospice is because actually I feel that although we're not able to make the patients better... those decisions are made and patients are kind of involved in those decisions and they're made early and appropriately (PCN6)</i></p> <p><i>And I just felt like I'd found- uhh, it sounds like such a cliché. It was as if I had this kind of like, erm, realisation that that was where I wanted to spend the rest of my career. That's where I wanted to focus on and it's since then that I've sort of moved myself into that aspect of care. Palliative and end-of-life care (PCN5)</i></p> <p><i>... I think... possibly... quite sort of, relatively successful I guess in the managing the sort of things that have happened, the dissatisfaction. Whether its healthcare, or the service, or just the situation. I think particularly with relatives, being able to diffuse that situation maybe. (PCN4)</i></p>
	Palliative care is personal	<p><i>If it, if it feels personal and and I think... depending on what's going on in your life, even with years of experience, things can feel very personal. (PCN1)</i></p> <p><i>I'm getting towards the end of my career. And I must admit that in the past perhaps two months, I have questions whether or not I can continue because it is taking such a personal toll on us all... on me in particular. (PCN2)</i></p> <p><i>So, I think I'm quite- well I am, at distinguishing between what stuff is mine to be upset about, and what stuff is somebody else's. And I think you absolutely couldn't do palliative care, or do it well, if you can't differentiate that. (PCN3)</i></p>
	Relationship with the patient	<p><i>Erm, and it is obviously, it's what we're here for, isn't it, is, we're here for that human factor, if we didn't want to work with people then we wouldn't, you know, be interested in building the relationships with them whilst we're caring for them I guess (PCN5)</i></p> <p><i>I think, I suppose, I suppose when I say, like, the less experienced staff, challenging decisions can be difficult for them. But I don't, I don't find them easy either... but you do it because you have to do it. And you are, I do see myself as very much patient advocate (PCN2)</i></p> <p><i>I think about in particular a patient who might be really afraid of dying, erm often that can result in them being quite agitated, erm, and I suppose my natural response to that is to sort of, try and be calming, erm, and just be present with that person (PCN5)</i></p> <p><i>I think it's, I suppose, trying to get through to somebody, knowing that I'm quite well and everything is fine for me and, and trying to relate I suppose on that level of what someone might be going through at that time (PCN7)</i></p>

The effect of affect

*I can use rational persuasion and I can do all that kind of stuff but erm, I have- you have to be where they're at. Which is hard. (PCN3)*

*...this guy was very similar age. And I opened the door and he was slim and dark like my husband is, and he had a [familiar t-shirt] on... and it absolutely took me off at the knees (PCN3)*

*It's generally when its people when I can put myself in their shoes... I've got young children so I always find young mothers with young children very hard to look after, or... anything where you can kind of... that could so easily be me. You project a bit, don't you? (PCN6)*

*But I'm not afraid that if I was in a house... I wouldn't cry and sob, but if I had tears in my eyes, I think that's okay. Because it does generate tears in your eyes... you know, the nature of the work we do is incredibly sad (PCN1)*

*it's actually quite an emotional response, even now. It feels quite a physical response to that from me, actually. And you know rational brain supersedes that after a few seconds (PCN3)*

*I mentioned before about gut feelings. You just feel something deep inside for somebody sometimes and it's just... gosh... this is, this is such a horrendous situation that these have found themselves in (PCN2)*

*Erm... it's a difficult one. I guess erm, I mean, yeah I mean I guess in our job the most common challenge is really sort of the emotional states... sort of quite life changing (PCN4)*

*Erm, so when I came out of that house, on that occasion and got in the car to drive back to the office and I was extremely, erm, well, I was very very emotional, I cried in the car on the way back to the office (PCN5)*

*You can only do that for a finite amount of time, you know... sitting there and absorbing everybody's distress and not feeling that you're helping with that is really really draining and you can't do that indefinitely (PCN6)*

*So, if you have tried all that and they're still emotionally distressed then that's difficult because you do reach a point where this individual might sort of die in emotional turmoil and that's really difficult. (PCN6)*

*I'm getting towards the end of my career. And I must admit that in the past, perhaps two months, I have questions whether or not I can continue because it is taking such a personal toll on us all... on me in particular. (PCN2)*

Defences, self-protection, and coping

*She's still with me, thankfully, but she went through cancer treatment so I think as a family we all felt it, and... we j- we just got on with it as you do...*

*So I think there's been a lot that's carried on and I've become one of those people that just... deals with what is today and just gets on with it really (PCN2)*

*But I think it's hard to have, um, um mechanisms to... um deal with that yourself. You've gotta find some mechanisms (PCN1)*

*And I think, like I've said before, about putting things in boxes. I'm not saying that I've got loads of issues but, I think you do just put it away (PCN2)*

**Feeling responsible, or feel as if what I have to offer is not enough**

The challenge of unaccepted care

*it was probably the last time I cried for a patient. And it is ages ago [laughing] (PCN3)*

*I think there is a temptation realistically to step back and not get involved, probably. And I never do, but I think realistically speaking you're probably gonna be slower to get to that referral or... and not necessarily spend as much time discussing it, erm. Yeah. (PCN4)*

*They were just going in – obviously giving him the care he needed – but we weren't spending that time that he probably would have benefitted from. (PCN7)*

*I guess, sometimes patients aren't receptive to care. (PCN5)*

*Ya know, they need social support but their behaviour means it's hard to give it to them. (PCN3)*

*Yeah, I think unfortunately there are some people who are harder to help when it comes to emotional things (PCN6)*

*and then you suggest a solution. I'm pretty sure that's gonna work, you know? And then they go "oh no, I don't wanna take that. No I don't really like tablets", and I kind of go- or they say "I don't take tablets" that's a classic, and I'm thinking "hmm, well you've never had this before have you? [laughing] (PCN3)*

*You know his past which is... unusual, difficult, challenging for him already, and you know, he's not in a good place, so... I guess it's just sad, like you think 'you don't need to be pissy with me because I'm here to help you, emotionally, you know... stop pissing me off erm... stop being rude, actually' but you go 'okay, he's allowed to be rude, we're just gonna have to ride this one (PCN3)*

*yeah, it's the more complex... it's difficult to define complex – we have this discussion all of the time, but you instinctively know when something is complex and it's never one thing, it's the multiplicity of things which make a situation, or a family dynamic complicated (PCN1)*

Responsibility and control

*Yeah, and I think... the responsibility... the responsibility for doing the right thing wasn't really mine, but I knew I had some opportunity and potential to influence that (PCN3)*

*Yeah, I think in these role people have quite high expectations of what we should be doing. And I think erm, expecting that no matter what is going on you've got time to just be with somebody. When the reality is quite often you're managing so many other, you're juggling so many things, to spend some time with people. (PCN2)*

*But I think, erm, just doesn't engage, I think, in a lot. He isn't realistic about his situation, erm in particular this is in relation to discharge planning. Realistic about him being able to cope at home, and then his son, although he's closest to his dad and sees him plenty, has kind of been distant from the planning of care. I think with the planning of other patients their family would have a long time ago stepped in and aid "look dad, this is unrealistic, you're clearly not coping at home (PCN4)*



*Interviewer: ...what happens in a situation where it's impossible to give a smooth, a smooth transition into dying?*

*PCN4: Yeah, yeah, it's a good question [laughs] erm... (PCN4)*

*all I wanted to do... if it was my friend I would be saying "yeah, you've got time, it's gonna work out for you" and trying to be positive, but you don't want to give anyone false hope and I don't know. (PCN7)*

Between fixing  
and being

*I think... it's not so much that I'm not... I don't feel uncomfortable with the distress, in dealing with it. It's knowing that I haven't resolved it that's uncomfortable. (PCN5)*

*probably frustration. I'm alwa-, err, I think I'm always very practically driven, so struggle a little bit when, erm, and I have this all the time like in previous jobs when people are very comfortable with talking about their problems but don't necessarily want to get to the solutions...*

*Erm, do you know, I think it's just a bit of hopelessness. Quite a lot of energy expended in all of that to end up with an outcome that feels like no progress has been made (PCN4)*

*So I did think it was appropriate to try and unpick what it was that she was upset about. She said "no, I'm not anxious, and I'm not worried about anything", so I said "do you want me to just sit?" and she said "no, I want you to help me feel better" (PCN6)*

*I think the kind of same feelings though, come erm from even, you know, not emotional things so like you know, even somebody who is just symptomatic control, I think I struggled a lot since starting really with management of like the nausea in particular because it's just very difficult to fix I guess (PCN4)*

Between failure  
and good enough

*But again, with reflection I thought that is saying something about him, and not about the way I handled that. Although I could've... handled it differently – you know I always think if something goes... because he was cross, I... I think you always have to reflect on how you've handled things and that's challenging too (PCN1)*

*But at the same time, it hurts, I think. It gets you on that very personal level that you've let somebody down, and that there's somebody out there walking around saying that that [palliative care] nurse was awful and didn't do what she was supposed to at the end. (PCN2)*

*And it's that feeling of real awkwardness, that you know you're not making this person feeling any better (PCN6)*

*I'm more thinking now about the kind of emotionally charged conversation and things, I think, erm, I think generally, just feeling very unsure really erm, of whether, you know, whether I said the right thing, whether I've been an adequate support (PCN4)*

*you're so desperate to get it right, and you're walking this tightrope the whole time trying to get it right, but actually it's... it's very difficult to do that. There's so many uncontrollable variable factors. Um, so I think you never come away thinking 'wow, that was a job well done' (PCN1)*

		<p><i>Yeah especially if you're trying your best. And I suppose that's in all nursing roles. More so if you try your best for somebody and it doesn't... it's just acknowledging that it's nothing that you're doing wrong and it's just that person and how they're feeling at that time. But it can be hard, definitely, and it can impact your day, definitely (PCN7)</i></p>
<p><b>Where my support comes from</b></p>	<p>Support and self-care</p>	<p><i>being in a small specialist palliative care team you've got to get on and support each other, and if you don't do that you really are on to a loser (PCN2)</i></p> <p><i>I would take some time off the ward if I needed to, and by that I mean go and have a cup of tea – not just leave. I'd talk to my colleagues (PCN6)</i></p> <p><i>And we do have conversations in the office about things we find challenging, so I think that's particularly helpful (PCN4)</i></p> <p><i>afterwards I guess you talk to your colleagues, see if anyone is having a bit more success than you and find out what you're doing differently. Talk about it at the MDT really, see if there's anything that we can think of that could help. (PCN6)</i></p> <p><i>Erm, but actually I kind of feel like it's more than that. You sometimes [need to step away] ... for your own erm... 'peace of mind' isn't quite the right phrase... for your own mental health I suppose. (6)</i></p>
	<p>Validation and containment</p>	<p><i>we still don't have a resolved those things, I guess, kind of opening it out to other, like, clinicians and colleagues, and kind of that confirmation that, yes, things aren't good, but there hasn't been anything obvious that we could have done to resolve it or improve it. It's a bit of reassurance. (PCN4)</i></p> <p><i>I mean I had a good manager at the time and we had a sit down and explored and went through responses to those questions (PCN2)</i></p> <p><i>that would have felt really personal I think 'oh I'm really failing you if you've come away with that impression'. And when I checked it back with her she said "no I don't really think you're trying to kill me, I'm just having a melt-down (PCN1)</i></p>
	<p>Professional issues and supervision</p>	<p><i>I've always found it to be really useful in being able to, I guess it's like re-packaging experiences and being able to see it from a different perspective (PCN5)</i></p> <p><i>Because normally what we would do is deal with that situation and literally move on to the next. You don't get a chance really to debrief or talk about what's happened. We don't get any supervision or anything like that anymore (PCN2)</i></p>

*patient had just been diagnosed and that they were being discharged and that they were going to start some [palliative] treatment ... it had been allocated to me and I went out to assess the patient but when I got there, erm, the patient was, was quite clearly, was dying, and erm, his wife wasn't at all prepared for that, or aware that that was the situation erm and no-body had had a conversation with her about erm, about end of life, about what to expect, about that, that could've been imminent, erm, and I, I guess I was left in this situation where I had a really complex situation to deal with so I had a patient who, who appeared to me, to be in the last hours of life ... I felt it was a dangerous discharge (PCN5)*

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### **The personal and emotional experience**

This superordinate theme captures the experience of participants that is more affect-focussed. Participants were often reflective and thoughtful about their personal story, and how it connects to their felt experience when in a challenging interpersonal situation with a patient.

#### *About me/ the reason I'm here*

Several participants acknowledged and reflected on their motivation for working in palliative care. Sometimes it was connected to freeing themselves from the risk of repeating a painful past experience, whereas for others it was described more simply as if it were their 'calling'. One participant powerfully shared that they had experienced significant and tragic personal losses repeatedly throughout their life, and recognised that this was a part of their choice to work in palliative care (quote omitted to protect anonymity).

*So, [laughing] maybe that's a part of the reason that I'm here and not still in the acute trust. But yeah, definitely some sadness and some anger about [what happened] ... you know, being here where I'm not expected to save anybody... that's probably a choice I've made based on the difficulties I've had in the past. (PCN6)*

Participants were similarly reflective about their time working in nursing, sharing how it had felt like a journey which had taught them how to care for people, but also how to care for themselves.

*I think I was really poor at self-care as a young CNS and as I've got older I think 'no, you shouldn't be doing that today, you should be, you know, seeing if someone else can be doing it' (PCN1)*

However there was also a powerful sense amongst participants that working in palliative care exposes you to potentially painful and existential fears.

*...it was just relating to that lady and imagining what she was going through and kind of going to a bit of a dark place thinking about I would cope with being told that news. (PCN7)*

*But every now and again something gets through that. And I know, even though I talk about death and dying all the time, and it puts it there (PCN3)*

### ***Palliative care is personal***

Participants spoke movingly about how personal palliative care nursing can feel, particularly in the context of challenging interpersonal interactions. Some participants expressed ambivalence about how affected they were, whilst others described much clearer ideas on the importance of differentiation.

*that would have felt really personal I think 'oh I'm really failing you if you've come away with that impression'. And when I checked it back with her she said "no I don't really think you're trying to kill me, I'm just having a melt-down" ... So, again it felt about her and not about me (PCN1)*

*But I think the separation, erm, you know that you're not feeling their pain, but it might have triggered pain in you. I think that's important (PCN3)*

Whilst another participant displaced their feelings to an external source, sharing that their political interests shapes their relationship to challenging situations at work.

*Erm, there's the situations and how you deal with it in the immediate, but then there's the bigger picture and how it relates to society. I think that, that hangs in my mind more so... I mean that again is probably personality driven. I'm quite involved in politics and things like that (PCN4)*

### ***Relationship with the patient***

Several participants expressed that attending to the relationship was an important feature of navigating challenging interactions with patients. This might take shape around building that relationship, or in the peripheral act of advocating for the patient.

*I suppose it's trying to build a relationship and trying to get in there a little bit just to calm the situation down. I think that can be really difficult, especially if they do not want to talk to you, and it's just another nurse. (PCN7)*

Though participants also used the space to reflect on the extent to which the *interpersonal* nature of the role can also become the basis of their more challenging experiences.

*I think you have to learn to be open to it. And sometimes that can hurt and it's what you do with that hurt, isn't it? And, and I'm really trying to work on that, it's a life long project. (PCN1)*

However it was clear that participants were meaningfully connected to this challenging reality, and nevertheless strive to keep trying.

*Although it's not, it's not ideal. And there's a lot goes wrong every time, but I feel we've come a long way myself and her, and I feel she trusts me implicitly. Erm, and I've argued her corner a few times (PCN2)*

### ***The effect of affect***

All participants shared something of their *felt* experience when thinking about challenging interpersonal situations with patients. It was common for participants to experience emotional distress as a challenge in their role. A particular feature of this theme however, was that participants all recognised that their role became much more of a challenge when they could *identify* with the patient in some way.

*She's one of those kind of matriarchs who everybody goes to and she sorts everybody else's problems out. So for her to be unwell is quite difficult, erm, and I get a little bit of that I suppose (PCN2)*

Participants were also able to connect to some of the feelings palliative care can expose them to. The process of thinking about specific events provoked live emotional responses for some participants.

*[patient] said "I can't go anywhere else, because when I die I need my soul to be near my children"... And I think I can hear my voice crack now [inbreath] [holding back tears], and it did with this district nurse, and she felt really emotional. So, I think, I am an emotional person and I... those things do touch you (PCN1)*

However some participants also recognised that when exposed to such potent emotional forces, one can reach their 'capacity'. Several participants used an 'emotional

sponge' analogy to highlight this experience. Or they reported having become 'desensitised' over time, such that they are rarely affected at all.

*And it's that sucking in of emotions over time, like little sponges, aren't we?*

*And... if you don't wring that sponge out then you can't take any more in, can you? And it's those mechanisms to wring, um, your emotions out, um, aren't always readily available maybe. (PCN1)*

*You can only do that for a finite amount of time, you know... sitting there and absorbing everybody's distress and not feeling that you're helping with that is really really draining and you can't do that indefinitely (PCN6)*

### ***Defences, self-protection, and coping***

Participants also made reference to the mechanisms they use to cope with the demands of their role; particularly with challenging interactions with patients.

*Yeah, I've had to kind of get a bit zen about it really (PCN3)*

*I think I've always been able to quite easily kind of disconnect myself from... especially like quite an emotional situation (PCN4)*

Though there was some sense of awareness that such mechanisms, whilst necessary, can also hinder the therapeutic relationship with dying patients.

*[self-protection] probably is... I don't know if that's very therapeutic always, but I think you have to have. You have to know your capacity, don't you? (PCN1)*

Extending from this position of understanding, some participants appeared to hold the patient responsible for the discomfort that was evoked in them - at least initially. And several



participants acknowledged that in a bid to look after the self, there can be implications for the patient and the care that they receive.

*I think initially you can – If I'm being honest, you know “what do you know” kind of thing. “I'm trying my hardest here and we're going through such a hard time as nurses” (PCN7)*

*...you do unfortunately find yourself perhaps withdrawing a little from the patients that are tricky. I try not to do that, but I think it's inevitable really (PCN6)*

However, one participant effectively summarised her view that the mind's way of coping with the overwhelming reality of death and dying is to avoid meaningful connection with it.

*we all go through life, don't we? Knowing we're gonna die, but not really thinking about it. Because if you were thinking about it you would probably be sectionable after a few weeks if you thought about it all the time (PCN3)*

### **When I feel responsible, or feel as if what I have to offer is not enough**

This main theme captures the powerful, and at times overwhelming, sense of responsibility that the participants experience in their roles. Participants shared openly that this feeling of responsibility is experienced internally, whilst also reinforced by their working context.

### *The challenge of unaccepted care*

The conditions described above appeared to set the tone for one of the key interpersonal challenges reported by many of the participants, which is around how it feels when a patient is unable or unwilling to accept the care being offered by them.

*I think for me, in that situation it is difficult if a patient is closed off and doesn't respond. (PCN5)*

*And there's obviously always people that, no matter what you try, you're never going to help them ... Yeah, no matter what you try to do, I suppose (PCN7)*

This perceived inability to respond to the care being offered was not a benign experience for staff, but in some cases could be expressed by patients with frustration, rejection, or by complaint. Nevertheless, PCN5 felt that one can still find a way to establish rapport.

*And he was quite, I suppose you'd describe him as quite obnoxious really, quite rude to staff, you know, he'd tell them to 'eff off' and call you names and stuff, erm, but still I think you can, you can still build a rapport and a relationship with, with people regardless of that. (PCN5)*

Participants also shared that a patient's family could generate tension with regard to the suitability of the care being offered.

*I'm thinking of a young woman that I'm seeing now. Even on Friday, her son was very angry and said "I don't want anything to do with the likes of you" essentially thinking that his mum is dying and somehow, you know, we're seen as part of that process (PCN1)*

In response to this challenging dynamic, participants reported feeling their own frustrations.

*Erm, and often leaves the whole healthcare team tearing their hair out.*

*(PCN3)*

### ***Responsibility and control***

Most participants seemed in some way affected by feelings of responsibility in their role, and this was expressed during interview in a variety of ways. Some were able to directly acknowledge it, whilst others shared something of their implicit burden of responsibility, believing that they can take control of something which is not theirs to take, albeit with good intention.

*It's just about, I suppose it's about taking on that level of responsibility and erm, and not being able to, to switch off from it (PCN5)*

*Usually, I find that I can get in there, definitely. I think most of it is how I've found that I basically say to patients "let me deal with the anger that you're feeling now, let me deal with that and I'll come back to you, and you spend quality time with your family that you deserve to, now" (PCN7)*

However, when working with dying patients, feelings of responsibility appear to have powerful and disturbing potential. One participant described a situation where they felt gripped and deeply affected by the responsibility for giving a patient and their family a chance of a good death.

*I was just really worried that he was gonna die in the midst of it all, without proper resolution of the issue. It was sort of- it was the thing, you know with*

*Cancer “oh yeah, we’re gonna treat you and we’re gonna do this other procedure”, and all I saw was this guy dying...*

*...It was that his medical plan wasn’t right and I just couldn’t move it forward and I’d tried it every which way. I’d rung on-calls and rung consultants that were on holiday in Barbados. And it was just, it was just a nightmare. (PCN3)*

For PCN3, it seemed necessary to develop a different relationship to this problem as a means to adjust and cope with their limitations.

*“So yeah... I read this thing the other week which said, ‘don’t accept responsibility where you don’t have authority’...And that just chimed with me, so... I don’t know who came up with it, but that’s- that’s how I contextualise and cope with it (PCN3)*

### ***Between fixing and being***

Amongst the participants, there seemed to be a common inclination towards the idea of ‘fixing’, whilst at the same time acknowledging a seemingly opposing reality that palliative care is not about fixing. This ambivalence was observed throughout the interviews.

*A lot of it is, like I said before, about wanting to fix things, a lot of nurses say: ‘Oh I wouldn’t want to work in palliative care because patients never get better’. Erm, but it’s never really been about that for me, it’s more about being able to care for them (PCN5)*

Whilst this ambivalence was an important feature, inevitably representing an important aspect of the psychological experience in palliative care, there was also a range of

different contributions to this theme. Some giving a sense of a concrete need to fix specific problems, whilst others represented a nuanced and subtle understanding of 'being'.

*I'd be assessing what their needs are, so looking at where the pain was... asking them you know, how they were feeling, erm, what their experience of the situation was, I'd be wanting to know where they were coming from in order to be able to problem solve (PCN5)*

*And I think it's less about doing and having solutions, and more about being (PCN1)*

### ***Between failure and good enough***

Many of the nurses interviewed carried a heavy sense of responsibility about doing a good job, providing a good death, and feeling successful in the role. The data highlights some of the ways that this can be experienced by the participants.

*The key thing was that I didn't want him to die without the family knowing it was gonna happen. (PCN3)*

*Yeah, I think in these role people have quite high expectations of what we should be doing ... When the reality is quite often you're managing so many other, you're juggling so many things, to spend some time with people. (PCN2)*

One participant reflected on the conflict of their internal experience, between what is rational versus what is experienced emotionally.

*I can say here that I know I can't make it right for everybody and I know that on a rational level. But on an emotional level you still want to make it okay for*

*people. And... and we can't, can we? ...I can't make it okay for... you know, for any children left behind. (PCN1)*

Several participants spoke movingly about how they regarded themselves as a failure in the context of a challenging interaction, or were left asking difficult questions of themselves.

*But actually it is one of those situations where you can feel a bit of a failure (PCN6)*

*Yeah, absolutely and, do I do a good enough job (PCN7)*

Indeed some participants described scenarios where they had to tread the delicate line of supporting a dying person who was acting out of their distress; responding in ways which appeared to have left them feeling conflicted.

*[in response to a patient who wanted to know if she would live for another ten years] I kind of went down the route of "treatment changes everyday, let's look towards that, let's keep positive", but I don't think I gave her the answers she wanted to ease her mind, you know? Because I couldn't. I did find that difficult, definitely (PCN7)*

*[in response to an abusive patient] You know, you wouldn't tolerate that. You know, in the kind of normal routine reaction, but the issue is - it isn't normal. It isn't routine. And where we've got to, to get to today is... you know... you're allowed to have your reaction to what's happening to you. (PCN3)*

When reflecting on challenging interpersonal interactions, few participants talked about feeling 'good enough', one was able to reflect on their journey in this way.

*I think with experience you learn being alongside is enough sometimes  
(PCN1)*

### **Where my support comes from**

This superordinate theme captures some of the participants' strong feelings about occasions when they felt unsupported or isolated in their roles. It also captures the opposite, and across interviews there was a common thread that individuals knew where they could find support when they needed it.

### ***Support and self-care***

Several participants described experiences where they had felt alone with a challenging situation, but some also acknowledged that it was the presence of a colleague that helped them to cope.

*in a situation like that, you can't do everything on your own, you have to call in  
the support of your team (PCN5)*

*It's quite obviously a horrible, distressing symptom for someone to go  
through and in those, those occasions where, so like when I, when I worked at  
the weekend when you're quite on your own really (PCN4)*

Some participants also recognised the value of an informal moment to debrief with peers along with some comforts.

*Erm well, so I got back to the office and there was colleagues there, other  
people on the team, erm, who, you know, they, it's what we do, you make a*

*brew, you sit down, you have a cup of tea and you talk about what happened, so that kind of informal support (PCN5)*

In some cases participants were thoughtful about their own limitations in dealing with a challenging interpersonal situation, and described the utility of handing over to a colleague who might be better suited to the patient's needs.

*You might get the support of a different member of staff because we're all individuals and someone else's individual style of how they might reassure or relate to a patient might just suit that individual better. (PCN6)*

### ***Validation and containment***

Participants also described important moments when, having gone through a difficult situation, they experienced containment or validation from their colleagues, bringing with it a clear sense of relief.

*The doctor who was on that day absolutely recognised what was happening, had the conversation with the patient and the wife, and I could have kissed him. And I was so relieved (PCN3)*

*So having somebody there to witness it, I think perhaps that's why that stays with me ... somebody was there that I respected that actually acknowledged 'gosh this is s\*\*\*, ... d'you know what I mean? That you don't normally get. (PCN2)*

There were also examples where participants felt that without validation from the patient, the role can feel less rewarding.



*Doesn't really matter what you do, their life's still awful [laughing], erm, everything's awful at the time [laughing], that can feel- erm so those mechanisms where you feel there's some reward as a professional, kind of aren't there. (PCN3)*

### ***Professional issues and supervision***

Most participants recognised that within their role, they are in some way negatively impacted because of perceived issues within the system as a whole.

With regard to clinical supervision, several participants shared just how much of a loss it is for them, but also how serious they felt an absence of clinical supervision was broadly.

*I have taken to therapy because I think they are stressful and I- our clinical supervision would have been a really good place to take that, but I haven't got a clinical supervisor anymore. We don't get clinical supervision. And there are lots of changes and I think it's a real travesty, actually. So I think I just found my own, and I think that's the only way to keep mentally well really ... definitely, I think without [clinical supervision] I, you know, there are times when I've thought 'how much longer can I do this job' (PCN1)*

However the relationship to clinical supervision is likely more complex, as some participants shared varying experiences.

*Erm, I think that's really important it helps, well for me it is. Not everybody. A lot of staff, erm, nursing staff, will kind of avoid clinical supervision (PCN5)*

*So, I haven't had [clinical supervision] for ages. I started with one person and found it really unhelpful, erm... it kind of aggravated the frustrations I was feeling and gave no solutions. But the one I have at the minute is excellent, but it's quite early with things. I'll see, I've got an open mind. (PCN4)*

Beyond supervision, some concerns were raised about how a lack of supervision is a symbol of a lack of care for staff and for patients.

*I think it's just an acknowledgement of what's happening at the moment and how we are treated, [interviewer name]. As a service how we've felt kind of – just get on with things and deal with it and don't make a fuss, and carry on. To the point where people then leave. (PCN2)*

*I think that corresponds with a dampening down of psychological therapies for patients, you know we stopped art and music therapies. And they've gone now (PCN1)*

With regard to professional relationships, some participants reflected on the nature of conflict amongst professionals which can lead to frustration. The instances described here carry with them serious implications for the availability and provision of appropriate care for patients.

*I was trying to get one of my district nurse colleagues to visit every night, and they were really acting off and saying they're too busy ... trying to say she should come into the hospice. And I said "no, she really wants to die at home", and she was saying to me "well if it's so awful for her at home, why does she want to die there?" and she had, this woman had said "I can't go*

*anywhere else, because when I die I need my soul to be near my children*

*(PCN1)*

*the family who have been led to believe their loved one is dying, and to go in and say 'they're very poorly, but I don't feel that they're quite at that stage right now' ... you're kind of raising expectations, aren't you? And then they question medical decisions and it brings a whole load of other challenges with it ... And then there's a lot of pressure as well, [interviewer name], about keeping quiet about that ...Because when we have questioned it with certain professionals – senior professionals - they haven't been happy (PCN2)*

### **Psychodynamic features**

Table 4 provides example quotes to highlight some of the psychodynamic concepts described in Table 2. Psychodynamic features are discussed further within the discussion section of this report. To protect the anonymity of the participants, I have removed the participant number from the quotes listed in the table below, as the psychodynamic features are more interpretative, tentative, and exploratory, and thus should be read as such.

Table 4.  
*Psychodynamic features and illustrative quotes*

Psychodynamic construct	Example quote	Context
<b>Denial</b>	<p><i>And I must admit that in the past, perhaps two months, I have questions whether or not I can continue because it is taking such a personal toll on us all... on me in particular...</i></p> <p>...</p> <p><i>are you going to be looking at how people cope in all this, in this sort of role. Not particularly for me, but for colleagues</i></p>	<p>The two comments here represented something of this participant's difficulty in sitting with the powerful and possibly painful reality of their relationship to their role.</p> <p>This is one example of them acknowledging the toll the work is taking on them, which then appeared to be denied later in the interview when suggesting that the support is needed for others – not for them.</p>
<b>Repression</b>	<p><i>And, and I think identification is... is less... I don't identify as much as I used to. And I don't know why that is</i></p>	<p>This participant seemed to value self-awareness highly as trait which supports their self-care: offering astute self-observations throughout the interview.</p> <p>That said, they appeared to have some ambivalence about what does and does not affect them, particularly around patient anger and <i>identification</i>. This quote seemed to effectively summarise the felt sense that repression may serve as a helpful defence against the inevitable increase of identification that would occur with ones own aging (and the reality that most patients receiving palliative care are older).</p>
<b>Reaction formation</b>	<p><i>I think I've always been able to quite easily kind of disconnect myself from... especially like quite an emotional situation – it's helps with being able to be honest and stuff like that which I think is really important</i></p>	<p>This quote explicitly acknowledges how they <i>disconnect</i> from the emotional content of a challenging situation. Throughout the interview was a theme of remaining unemotional. This quote may be an example of reaction formation to this experience – placing high importance on the utility of remaining unemotional.</p>
<b>Undoing</b>	<p><i>A lot of it is, like I said before, about wanting to fix things, a lot of nurses say: 'Oh I wouldn't want to work in palliative care because patients never get better'. Erm, but it's never really been about that for me, it's more about being able to care for them</i></p>	<p>This participant explicitly stated at other points in the interview that they have a tendency to want to fix things. This comment seems to be an attempt to neutralise the tension that this position generates.</p>

**Idealisation**

*They tend to have this idea of what a [palliative care] nurse is, and it's kind of like "the angels are here" and if you don't have a good experience I suppose it's... that's why they can become angry as well*

This quote is a clear example of how idealisation was woven throughout the interview discourse. This participant seemed aware of how far one might fall when they are unable to meet the impossible standards of being an 'angel'.

**Omnipotence**

*So even if somebody's refused to make a plan, refused to engage with the fact they're dying, refused what symptom control we offer. Even if they've been the most difficult and awkward, at some point they will just start dying*

Throughout interview the participant who gave this first quote spoke clearly about the challenges of feeling responsible in the context of palliative care. It seemed clear that this was an area of difficulty and had caused significant personal distress in the past. Omnipotence can be understood as a defence against a painful reality of helplessness. This quote seemed to illustrate a way of coping with the feelings associated with responsibility.

*It's just like, uh, um... if we've made that decision that this person is dying, they're dying and let's get on with it, cause then we need to make up room for other people to come through*

This second quote, from a different participant was summarising the position of the wider system and organisational pressure, where omnipotence can aid a system in managing the many overwhelming demands.

**Splitting and projection**

*I don't think he'd be particularly valued and would kind of probably be seen as more of a burden [by society] than anything else, so... And when you put people into that kind of... you know, it's the typical kind of thing you do with vulnerable people, isn't it? You know, they're vulnerable, they need help, but they need to fit into these boxes, and, and he doesn't fit into any of those boxes, so he's more kind of one that slips through the net...*

These quotes appear to illustrate a 'splitting off' of feelings about how patients can be treated. On the one hand this participant points to society as the problem in the poor treatment of particular vulnerable (or challenging) people. However later they acknowledge that they too feel drawn towards a position of stepping back and enacting the very conditions where a patient might 'slip through the net'.

...  
*I think there is a temptation realistically to step back and not get involved, probably. And I never do, but I think realistically speaking you're probably gonna be slower to get to that referral or... and not necessarily spend as much time discussing it, erm. Yeah.*

These quotes capture a theme for this participant of looking outwards as a way to respond to more personally directed questions (which are inevitably more challenging to answer).

**Projective identification**

*...this guy was very similar age. And I opened the door and he was slim and dark like my husband is, and he had a [familiar t-shirt] on ... and it absolutely took me off at the knees*

This quote demonstrates a very common theme across participants. This participant attributed an internal experience to the patient (*projection*) and related to them as if they embodied the projection (*identification*). The interactional force of this dynamic can result in the recipient acting in a manner congruent with the projection.

**Acting out**

*if it's a negative experience then you are less likely I guess to, to engage in that, and I think erm, sometimes there is that, a little bit of a blame culture in some nursing teams*

*I've found a bit of withdrawal from the patient. Because staff find it so difficult when they feel they're not getting anywhere and they're not helping. And I do see... you know... and I hold my hands up myself as well as other people... kind of trying not to engage as much with that patient if it gets to the point where you just feel like you're getting nowhere*

These are both examples of quotes which could be understood as acting out. The first acknowledges that when faced with a negative interpersonal experience, one is more likely disengage from that patient, but then to attribute the problem to colleagues in what was described as a blame culture. The second quote appears to be another example of this way of coping with a difficult feeling.

## Discussion

The aim of this study was to explore how palliative care nurses experience challenging interactions with dying patients, and the emotional impact of such experiences. A secondary aim was to explore the extent to which these experiences can be explained by psychodynamic constructs and theory. Findings illustrated that participants were typically drawn towards responses which captured something of their own powerful affective experiences; conceptualising ‘challenging interactions’ as ones involving an unpleasant emotional exchange. Those in palliative care nursing are regularly faced with difficult situations and recognising the emotional impact this has is important (Brighton et al., 2019). Many participants were open and vulnerable when talking about the way such interactions touched closely on their personal stories of loss and grief. Katz and Genevay (2002) acknowledge that only when we are comfortable grieving our own losses can we adequately help patients give voice to their overwhelming grief (p. 328-329).

The relationship with the patient was acknowledged as a key mediator when navigating interpersonal difficulties, but there was a particular sense that one must be willing to *feel* in relation to the patients’ distress in order to achieve meaningful connection - however painful this might be. Indeed, a study by Parola, Coelho, Sandgren, Fernandes and Apóstolo (2018) also found that nursing in palliative care is deeply relational and only when person-to-person relationships are established can nursing be most effective. Albeit, they conclude by saying it is an experience both rewarding *and* exhausting.

Participants were also able to reflect on the strategies and defences that they were conscious of using as a means for coping in their roles, recognising how necessary such mechanisms are, but also how unhelpful or ‘untherapeutic’ they can be. In addition to participants’ own sense making around defences, the author tentatively highlights

psychodynamic features of which the participants may be less aware. For example, where several participants seemed aware of their desire to withdraw from a patient when confronted by interpersonal challenge, it may be less clear to them that this could be part of a splitting and projection defence. In the case of one participant (described in Table 4 in the 'splitting and projection' row), such a defence enables the mind to take issue with society as the source of a problem, whilst being free from having to meaningfully manage its own painful feelings towards the patient.

In a chapter describing the inevitable mixture of feelings experienced by health care staff, Ballatt and Campling (2011) illustrate the value and utility of examining and acknowledging defensive processes, for the sake of both nurse and patient (p.59-60). A notion supported by several other authors writing on the psychodynamics of palliative care (Katz & Genevay, 2002; Speck, 1994; Timmermann, Naziri, Etienne, 2009).

Another key challenge that emerged in the data was around the sense of responsibility that participants feel. Specifically, the challenge was centred in the profound feelings of failure and hopelessness that would arise in the event that a perceived objective should not be achieved. Examples included if a patient is not easily satisfied, or in the event of anything besides a 'good death'. This finding is consistent with Kristjanson et al. (2001) study which found that nurses are profoundly affected by experiences of perceived 'bad death', such that they can experience accumulated grief in response to the continuous nature of the work. Findings also suggested that facilitating a space for reflection and processing can protect against accumulated grief.

There was a clear sense of many competing conflicts within this theme, such as; seeking control, but overwhelmed by responsibility; a desire to fix, juxtaposed against a reality that palliative care is not about fixing; a striving to feel effective in a context where



death is always the painful outcome. Indeed it has been reported that in conditions of high pressure and competing demands - both psychological and occupational - the risk of burnout increases for nurses (Gómez-Urquiza, et al., 2020). Furthermore, when under conditions of heightened emotional distress the propensity to rely on potentially harmful defensive strategies is greater (Lemma, 2003, p.206). That said, a study by Zambrano, Chur-Hansen, and Crawford (2013) found that whilst the stressors of palliative care put staff at risk of burnout, those interviewed had adopted coping strategies which emphasised meaning and rewards in their work, thus mediating the risk. This study also found that participants benefit from such strategies, and several participants described the privilege they consider their role to be.

Another way that participants conceptualised their experience of interpersonal challenge involved the structures around them, and more broadly around the health care system as a whole. Emerging from the data was a keen awareness amongst participants that the only way that one might survive in such an affecting context is with support. This finding is supported by Parola et al. (2018) whose findings emphasised the importance of the team as a pillar of support.

Participants spoke movingly about experiences of difficulty with patients which were either exacerbated or alleviated by the relative absence or availability of colleague support. A particular area of concern was around the issue of no clinical supervision, with several participants suggesting that the withdrawal of clinical supervision has negatively impacted them. Studies have illustrated the importance of providing clinical supervision for nurses in palliative care (Edmonds et al., 2015) as a source of care and for team wellbeing, but clinical supervision in nursing has also been associated with effectiveness of care (Snowdon, Leggatt, and Taylor, 2017).

## Limitations

This study has been conducted, in part, on the basis of psychodynamic theory which emphasises the importance, function, and potential impact of unconscious processes such as defence mechanisms. Indeed, psychodynamic theory describes - and empirical evidence points towards - the existence and influence of such mechanisms/processes, thus giving adequate merit for the present study and its tentative interpretations. Nevertheless, readers with differing epistemological or theoretical interests may regard the data here with different interpretation. As highlighted throughout, the interpretations offered here are tentative and intended for the reader to reflect with the hope that it might offer new understandings and/or meaning, or that it might inspire further research.

As a result of difficulties with recruitment, participants were recruited from different areas of England. As such they were working in a variety of different contexts and thus their respective experiences will have in some way reflected these differences. Participants also differed significantly in terms of their age and experience in the role.

Another important limitation to note is that participants may have volunteered because the study advertisement appealed specifically to a particular experience or interest. As such it is possible that those who took part represented an experiential niche within palliative care nursing populations. That said, IPA methodology is interested in the *individual* and is cautious to extend findings to wider populations.

An additional limitation is the influence of the researcher on the process of interview and analysis. Attempts have been made to make conscious those variables which might affect the findings, but even with the most rigorous attempts for transparency, there will inevitably be the unavoidable influence of the researcher's own interest and beliefs embedded throughout.

A couple of the participants lightly commented that the process of interview felt similar to therapy. This brought to mind that the researcher is a trainee clinical psychologist and thus the interview style may be shaped by experience of delivering psychological therapy. Furthermore, it was explicitly stated that the interviewer was also the primary researcher, perhaps influencing participants' sense of freedom within the interview.

### **Clinical implications**

The present study has highlighted several important implications for clinical practice, particularly centring on the issue of staff support. In this study, several participants reported feeling as if they might not be able to continue in the work, pointing to pressure and lack of support as reasons. Together with the absence of clinical supervision as a crucial source of support for some, there was the explicit risk of burnout amongst those that were interviewed. Furthermore, if similar patterns are happening more widely across palliative care services, the risk of burnout would be a much more significant concern for reasons which extend beyond the individual.

As described above, the psychodynamic features identified here are not the primary focus of this study, but rather a tentative exploration embedded within the IPA process which is intended as "speculations about mechanisms at play in complex areas of human behaviour and pain" (Ashby, 2017, p.221). Ashby goes on to suggest that psychodynamic exploration opens the opportunity to acknowledge, understand and process strong personal forces which have the potential for better health for individuals and their organisations. With this in mind, it may be clinically beneficial to find a way to offer supervision to give voice to psychodynamic insights that could offer richness to the caring experience.

## **Research implications**

This study was originally intended to capture the experiences of clinicians working within a single palliative care service. This will have included not only nurses, but also doctors and other qualified clinicians who will undoubtedly experience many similar, and many different things that would be valuable to learn explore. Future research may wish to attend to a different professional group within palliative care in order to deepen our understanding of how interpersonal challenges are experienced across professions, each with unique histories, expectations, and demands.

Future research may also wish to explore further the psychodynamic elements captured here, but more explicitly using a methodology which enables theory-based constructs to be a more central focus (for example ‘The Psychoanalytical Interview as inspiration for qualitative research (Kvale, 2004)).

Another potential avenue for future research would be to explore in depth the themes of this study. One such example could be in relation to palliative care nurses’ experience of clinical supervision, which might deepen understanding of what clinical supervision offers to some, yet feels too painful for others.

## **Conclusions**

This study explored how a sample of palliative care nurses experience and make sense of what they perceive to be challenging interactions with dying patients, with particular interest in the emotional impact of such experiences. The qualitative approach of IPA allowed for an in-depth exploration of the lived experience of staff, from their perspective. However this study took methodological guidance from Dennison (2016) who effectively strategized an approach to IPA which includes an element of psychodynamic exploration to enrich the

data with tentative interpretations from the researchers own understanding of a psychodynamic theoretical perspective.

Interpersonal challenges were experienced by palliative care nurses as emotionally difficult and painful, activating their own anxieties about being good enough. Nurses shared their complex experience of responsibility over the difficulties faced by patients as they approach death, and for some this sense of responsibility contributed further to feelings of failure. Participants commonly reported that the support of their colleagues was sustaining, though it emerged that the absence of organisational support in the form of clinical supervision put staff and patients at risk. A role for psychodynamically-informed supervision is suggested as one intervention, though it seems of tremendous importance that nurses are offered support generally, in a way which is embedded within the role.

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**Appendix A. A table to show key features of included studies**

**Table 1: Key features of included studies**

<b>Study</b>	<b>Location</b>	<b>Participants (n)</b>	<b>Method of analysis</b>	<b>Format of data collection</b>	<b>Key theme(s)</b>
1	Pelotas, Brazil	Oncological palliative care professionals (6)	Hermeneutic phenomenological	Interview	Meaning in the work // Spirituality as a therapeutic resource // Spirituality and training
2	Flanders, Belgium	Nurses from multiple specialist palliative care contexts (21)	Thematic analysis	Interview	Focus of care on living or dying // Content of palliative care // Nurse-patient relationship //
3	Ontario, Canada	Palliative care nurses: Home care (4) PCU (5)	Thematic content analysis	Interview	Experiencing distress // The importance of presence // Valuing the team // The need to know more
4	Canberra, Australia	Palliative care professional (25) Patient relatives (7)	Thematic analysis	Interview	Mismatched expectations and suboptimal communication // Not feeling prepared for death // Concerns about care // A hurtful experience not to be internalised // A proactive and systemic approach to conflict resolution
5	NSW, Australia	Palliative care professionals (28)	Grounded theory	Focus groups (x4)	Death is difficult in any language
6	Australia	Palliative care professionals (60)	Thematic analysis	Questionnaire (open questions)	The advanced care directive (ACD) // The process of developing ACDs // Process of using ACDs // Consequences of having ACDs
7	England, UK	Clinical nurse specialists: Palliative care (5) Cancer (5)	Hermeneutic phenomenological	Interview	Importance of relationships // Perspective taking // Ways to break significant news // Feeling prepared and putting yourself forward
8	England, UK	Palliative care professionals (6)	Interpretative phenomenological analysis	Interview	Professional views and on disgust // The personal experience of disgust // An empathic connection makes them vulnerable // Working in palliative care // Coping with disgust

9	Portugal	Palliative care nurses (9)	Descriptive phenomenological	Interview	Experience centred on the relationship with the other // Experience centred on the relationship with one's own self // Exhausting experience // Rewarding experience // The team as a pillar
10	Western Canada	Palliative care nurses (14)	Grounded theory	(telephone) Interview	Results suggest that <i>hope</i> is very important to PC nurses. It helps them to persevere and sustains them when faced with work life challenges. The main themes of these experiences included: Who I am // Resigning myself to the system // Feeling valued/respected // Managing grief and loss.
11	Not stated	Palliative care nurses (10) MICU Nurses (6)	Constant comparative analysis	Interview	Not described in themes. Nurses had different perspectives and experiences with palliative sedation. Some felt it hastened death, others did not. Some felt it was too close to euthanasia. All agreed it positively contributed to quality of dying.
12	Australia	Palliative care occupational therapists (6)	Interpretative phenomenological analysis	Interview	Knowledge of self // Giving permission for connections and feelings // Filtering experience // Being present at work and at home
13	Sweden	Palliative care physicians (18)	Content analysis	Focus groups (x4)	Challenged by the concept and content of breakpoint communication // Experiences of proactive breakpoint communication // Uncertainty affecting breakpoint communication
14	Canada	Palliative care nurses (7) Oncology nurses (4)	Interpretative phenomenological analysis	Interview	Death Confrontation: Meaning of Death // Spiritual-Existential Experience // Caring Attitudes
15	Adelaide, Australia	Palliative medicine specialists (7)	Thematic analysis	Interview	Being with the dying // Being affected by death, and dying // Adjusting to the impact of death and dying.

*Note.* PCU = Palliative care unit; MICU = Medical intensive care unit

## Appendix B. CASP Quality appraisal.

Critical Appraisal Skills Programme qualitative checklist (CASP) UK (2018) was used in order to allow for ready comparison of quality across identified studies.

Table 2: A Summary Checklist of Quality Appraisal

Study	Are the results valid?						Results		
	Was there a clear statement of the aims of the research	Is a qualitative methodology appropriate	Was the research design appropriate to address the aims	Was the recruitment strategy appropriate to address the aims	Was the data collected in a way that addressed the research issue	Has the relationship between the researcher and participants been adequately considered	Have ethical issues been taken into consideration	Was the data analysis sufficiently rigorous	Is there a clear statement of findings
1	Y	Y	Y	Y	Y	P	Y	Y	P
2	Y	Y	Y	Y	Y	Y	Y	Y	Y
3	Y	Y	P	Y	Y	U	Y	Y	Y
4	Y	Y	Y	Y	Y	N	Y	Y	P
5	Y	Y	Y	Y	Y	Y	Y	Y	Y
6	Y	Y	P	N	P	Y	Y	Y	Y
7	Y	Y	Y	Y	Y	U	Y	P	Y
8	Y	Y	Y	Y	Y	P	Y	Y	Y
9	Y	Y	Y	Y	Y	Y	Y	Y	Y
10	Y	Y	Y	Y	Y	U	Y	Y	Y
11	Y	Y	Y	Y	Y	Y	Y	P	Y
12	Y	Y	Y	Y	Y	U	Y	Y	Y
13	Y	Y	Y	Y	Y	U	Y	Y	Y
14	Y	Y	Y	Y	Y	U	U	Y	Y
15	Y	Y	P	Y	Y	U	Y	Y	Y

*Note.* Adapted from the Critical Appraisal Skills Programme (CASP) UK (2018) checklist for qualitative research. Y = The criterion was met. N = The criterion was not met. P = The criterion was partially met. U = It was unclear from reporting whether the criterion was met.

**Table 2 cont. : A Summary Checklist of Quality Appraisal**

Study	How valuable is the research?
1	The research does not make implications for practice clear. The discussion and conclusion suggest there is a place for spirituality in health care and in palliative care particularly. Infers more about the patient than is reasonable when interviewing staff.
2	Clear links between the data and subsequent discussion. Clear outcomes and recommendations about how the findings can be used to influence policy and practice.
3	There is a comprehensive discussion around the results, and implications for practice. The main implications are surrounding training interventions and better inter-professional relationships to enhance care provision.
4	Discussion and conclusions clearly link to the data and draws on concurrent literature. Very clear practice implications. Some examples of theme summary which do not seem to quite fit the example quotes.
5	Clear implications for practice derived from the data which would be useful locally, but in palliative care generally.
6	Recommendations concerning the use of advanced care directives (ACDs), as this was the focus of the study. Results highlight that ACDs can be useful, though work needs to be done to address issues in applicability, availability, relevance, and quality.
7	No clear implications described, which is consistent with the qualitative approach – appreciating the uniqueness of this study in this context. Nevertheless, a useful summary of the tensions that can operate between the personal and the professional lives of nurses.
8	Results provide a framework by which to understand the likely experiences of those working with disgusting symptoms and suggestions for developing support structures. Possible implications for patients' and professionals' psychological well-being.
9	Thoughtful and honest account of the experiences working in palliative care. No direct implication for practice outlined, but undoubtedly a validating and interesting account which could be useful to any practicing palliative care professional.
10	Generated a theory about hope in palliative care which the authors feel is applicable to other nursing contexts. Theory based firmly in the data, but at times felt as if positioned primarily in an optimistic space, which might not reflect all experiences.
11	Clear findings highlight clear ethical and emotional struggles for staff. Implicit implication might be that there is a need for support in helping nurses to process the internal experience in response to palliative sedation. Especially for nonphysical suffering.
12	Affective account of grief experiences in OTs working in PC. Talks about the value of feeling emotionally connected to patients, and how to then process the experience, and how it adds value to the role. Clear implications given for OT practice.
13	Some clear recommendations for practice and process around 'breakpoint communication' (which is the process by which a physician delivers news of significant change in prognosis/presentation).
14	Thorough analysis and good depth of thought about the experiences of nurses with death confrontation. Some practical implications, but more of an acknowledgement that individual experiences may vary and deserve careful thought and attention.
15	No explicit implications for practice. Acknowledged that the study focussed only on physicians within one city, but found many shared characteristics amongst the experiences described, thus may be useful for training or continued professional development.



## Appendix C. A table of quotations to further illustrate themes

Table 3: A table of quotations to further illustrate themes

Theme	Subtheme	Paper	Quote
The personal and the relational experience	A relational environment	2	<i>“Actually, we listen to the patient and their family, what they bring up, what they need”</i>
		7	<i>“if you do listen, you do try to understand, then very often you can work as a partnership and that's when best care takes place”</i>
		7	<i>“It's sad, but on the other hand you often get really... meaningful relationships with people but you may not have met before... in this short space of time this, this atmosphere of complete trust can, is often created”</i>
		3	<i>“There is certainly a component of being with delirious patients that we have to think about, not just in a pharmaceutical sense, but being able to be with somebody and be calming by your presence”</i>
		12	<i>“I honestly feel like when you get that connection with somebody it can blot out all of the rest of the stress”</i>
		4	<i>‘Suboptimal communication about disease progression (including managing pain, and nutrition/hydration) alongside insufficient clarity regarding the level of care provided by the service, create a context where conflict can flourish’</i>
		13	<i>‘Timing was described as one of the most difficult components to consider regarding break point communication. When the “right time” was never found, break point communication was not conducted’</i>
	4	<i>“I was trying to explain to him [...] if you were to take enough medication so you didn't have pain when you got up to walk, it would make you like a zombie and he took exception to the word zombie”</i>	
	4	<i>‘A history of drug and alcohol use, and severe and enduring mental health problems were also considered warning signs by staff [of a possible challenging relationship]’</i>	
	The personal and the professional		9
15			<i>“She'd made me feel vulnerable, because of the fact that she had children the same age, and I could see myself, I wasn't that much older than her then, and I could see myself in her shoes and identified with her in a way”</i>
12			<i>“The thing that I have to be mindful of my triggers is actually that (in) those cases sometimes I can invest a bit more time and effort”</i>

		9	<i>“This experience, in sentimental terms, requires a greater involvement on our part; people are usually in a critical phase and get more involved with us... and I also end up becoming more involved in a conscious way”</i>
		7	<i>“... you know, my father had cancer and I nursed him. And I saw how health professionals interacted with him and I saw how often they had no clue whatsoever through his personality or how he'd want to interact with someone”</i>
		14	<i>“It's a chance. I experience something, intense, real, and I want to integrate it into my life... I grow spiritually in my quest for being what I want to be. I have no choice but to be in real contact with my values and priorities”</i>
		14	<i>“...participants seemed to experience significant distress... This was especially true for nurses who ... recently suffered from major and non-integrated loss, such as the death of a loved one, divorce, or other, for which they could not find meaning yet”</i>
	Spirituality and meaning	15	<i>‘Religious and spiritual interpretations were comforting for those with religious beliefs... participants with religious beliefs, who worked with atheist or agnostic palliative medicine specialists, stated an inability to understand how those colleagues could deal with their work’</i>
		1	<i>“Spirituality strengthens me as a person and as a professional... without spirituality, much of what we do would have no meaning... it enriches us a lot as professionals and greatly enhances the care”</i>
		14	<i>“I don't think that to get up, to eat and to go to work is enough to face all the emotional stress that we experience in the kind of work we do. I am also a human you know... when you face somebody in profound distress and when there is no answer to their questions... you need to find something else that's within yourself to help... maybe that's what spirituality is”</i>
		14	<i>“Nurses also felt that their privileged role allowed them to achieve a sense of purpose in life... life doesn't belong to us. It can be taken away at any time. Therefore that's what motivates me to do something real: to help other people... so my short life is meaningful”</i>
		14	<i>‘Many of them also did not attribute meaning to death. They wished they had beliefs they could hang onto in difficult times, but could not find any’... “I used to pray. It used to reassure me. But now, I am alone doing it and it doesn't make sense”</i>
<b>The organisational experience</b>	The nature of the work	5	<i>“There's a lot of challenges but... to feel like you've negotiated those challenges and that they're feeling more comfortable, that's a very satisfying feeling”</i>
		11	<i>‘The use of palliative sedation for the patient's nonphysical suffering was a difficult issue for [some] of the nurses. They struggled with it because they felt that this type of suffering was beyond their expertise’</i>
		15	<i>“Being a palliative care specialist was considered as an opportunity to know patients and to be present in a way that no other medical specialty or health profession could”</i>
		9	<i>“I always value what he wants to do. If he wants to take a shower, he does. If he doesn't want to, he doesn't. If he wants to eat, he eats. If</i>

Organisational  
processes

- he doesn't, he doesn't... my care at that moment is focused on what the patient wants, not what I try to do routinely"*
- 13 *'Reasons for feeling uncertain included a lack of experience with palliative care, a lack of experience or training regarding communication and a lack of knowledge about how to handle demanding dialogues'*
- 7 *"...I find it difficult, the fact that we know the information before [patients] and I know that we do because we discuss them at [multi-disciplinary team meetings]"*
- 11 *'Nurses who self-reported little experience with palliative sedation struggled the most with the 'fine line' between palliative sedation and euthanasia... "I remember having questions about – because it was all new to me – what was an appropriate intervention? Was this euthanasia? Was this physician-assisted suicide? Was I being asked to actually kill a human being?"'*
- 4 *'The disjuncture between relatives wishing to give the patient food/fluids contrasted with clinician prioritisation of the potential risks of aspiration or choking... "Hydration is a big thing and that ties back to ... level of expectation of the loved ones and really having being told what is happening"'*
- 14 *"I had a patient; he didn't even want to talk about it. I tired of asking him; maybe you realised things within the last month, maybe you want to say something, maybe write to your wife or kids? He didn't want to. He didn't want anything. Some of them also refuse to see it, to accept it. They are totally blocked. I try to get them prepared so we can intervene, but it's like there is nothing to do with them"*
- 14 *'It appeared that patients' experience of suffering, distress and despair was incongruent with nurses' positive attitude towards life and death, as well as with their desire to infuse their patients with their hope and meaning'*
- 2 *"The possibilities are often very limited. We don't have the opportunity to intervene... usually all we can do is limit the damage. By looking after them as well as possible. That is palliative care"*
- 10 *'participants... were not feeling as if they were able to make a difference when dealing with numerous challenges in their lives and external work constraints (e.g., lack of autonomy, lack of collegial support, restructuring of care delivery)'*
- 13 *"I did not feel prepared for it all. I do not remember anything from my training/education about [end-of-life communication]"*
- 1 *"We are not prepared during our training and throughout life...When patients wanted to talk about spiritual matters, transcendence and the death process itself, we refused to talk about it"*
- 3 *'Teamwork was viewed by both [palliative care unit] and home care nurses as enhancing the quality of care for the whole family'*
- 9 *"There are always situations that raise doubts in me and that I sometimes cannot solve by myself, and I turn to the team. And there are things that are sometimes hard to accept; we need to speak to each other"*

<b>Coping with death</b>	Coping in a palliative care context	4	<i>"I step back to be calm inside, but I'm usually angry. It depends what it is... what I try to do is I think 'well it's not that personal to me'"</i>
		7	<i>"There have been situations that, unfortunately, were not so peaceful, and then yes, we go home, and we are disturbed by them... but there you go! We have given everything, we have done everything, but it is not having an effect... then it becomes a moment of anguish"</i>
		12	<i>"so if somebody has died then thinking about the time that we spent together and the memories that they'd shared with me or the wishes that they'd shared with me. And thinking about if there was something that I had done that might have made a difference to their life and to their experience and getting some reassurance from that"</i>
		7	<i>"when I first started doing this job, I found it really, really hard ... As I've gone through the years, I've started ... you have a bit more of a wider experience about people's reactions and how they react to bad news and you, I suppose I've learned to deal with it ... it's just experience"</i>
		10	<i>"to me keeping the positive aspect of hope is important. I think that's how I do a lot of the definition of hope, is through the optimism, being positive and everything in the negative side kind brings it down"</i>
		14	<i>"The values I pass on to my kids, and the positive attitude I try to inspire my colleagues with, are going to last after my death. That's why I do everything I can to spread my love around me"</i>
		8	<i>"once I've done the symptom management, the bit that I'm really there to do, anything else that I can give thereafter is a bonus. So if the bonus on that day is only a small bonus, then that's the way it's got to be"</i>
		Confronted by death	
9	<i>"There is always a time when we face our own death"</i>		
14	<i>"My ex-husband, he talked about himself a lot... my actual boyfriend... he always says everything is okay... there is no space for a deeper connection. I can't even tell when he's happy or not... and if I am happy, it's okay. If I am upset... it's still okay... empty, yes, that's how I feel, empty . . . (crying). I am sorry... every time I really talk about myself to someone, I cry. I don't know why"</i>		
3	<i>"They wanted to control the patient's severe symptoms so that family members would not be left with final disturbing memories" "and you don't want this moment, that episode, to be how the family will remember them. It's part of a continuum, it may be almost the final part and we don't want people to have that memory"</i>		
11	<i>"We were treating symptoms that could not be treated in any other way... We did him the better service by getting him comfortable than when we shouldn't have done that at all. Maybe he would have lived a couple of days longer, but then he would have been very uncomfortable"</i>		

<b>Defensive processes</b>	Denial	9	<i>"It changed the way I often face life in the face of a problem, and I think: This, it's just this! If I was like one of my patients, I'd be much worse"</i>
		14	<i>"When I enter a patient's house, I say to myself: I am who I am. I won't be different because they are dying and because they face challenges. I won't put a mask on my face. I won't move to pity. I talk about life with them!"</i>
			<i>"Conferences or in-services, I don't dislike those but often it is at the end of day and I get there and I am so tired that the information does not even go in"</i>
	Reaction formation	14	<i>"One of [the patients], she just cries all the time... and she calls me... and I had this couple who wanted to commit suicide together... So I just spent so much time with them on the phone. I am not a psychologist!... I am exhausted... Maybe it's guilt... Maybe I don't do enough or I don't do the right things..."</i>
	Omnipotence	14	<i>"Sometimes I drive my patients to think about daily little pleasures... hum... Not just to think about nausea, pain or constipation related to their state. All of those difficulties... there is always something in every moment that's worth living and we have to look for it. So I say to myself, if my patient gets his little pleasure today, even with the diagnosis that's full of symptoms, it is perfect! We won!"</i>
		7	<i>"... you're more competent at it and therefore obviously you put yourself forward to be involved more than you would have done in the early years"</i>
		8	<i>"You're different from the person in the street who won't look at them, or that charity workers who go there, you're able to hold it... They all disintegrate, because, you know, telling someone they're going to die,[...]. So you're sort of sitting there in the middle of this, sort of holding it"</i>
	Rationalisation	8	<i>'Interestingly, participants did not use the word 'disgust', instead they used terms referring to a difficulty, such as 'hard''</i>
	Splitting and projection	14	<i>"I can't understand why you decide to spend your life being angry . . . You can't put pink glasses on somebody who doesn't want to see how beautiful life is"</i>
		15	<i>'Participants down-played the negative impact of dealing with death and dying by reframing their experiences in a way that highlighted positive meaning, both for their patients and themselves'</i>
	Projective identification	7	<i>"...she was you know having her first baby. She'd just got married... just starting this new chapter in her life and then to be told that she's, you know, she's got maybe a few years to live is just awful ... she's not that much you know similar age probably to me ... I suspect that's harder to rationalise I suppose in your brain"</i>
		4	<i>"A patient felt he wasn't being given his medication... And he became aggressive and wanted to leave so he became quite threatening and yelling"</i>

## Appendix D. Statement of positioning and epistemology

Epistemology is concerned with how we know what we know, and involves thinking about the nature, scope, validity, and reliability of claims to knowledge (Willig, 2008). A researcher's epistemological position will be informed by their own view of reality and thus when conducting research (which is itself a pursuit of knowledge), there will be inevitable interplay between the researcher, their view of the world, their epistemological position, and the method of research employed (Creswell, 2013).

At one end of the epistemological continuum is the empiricist and positivist position, which suggests that the relationship between the world and our understanding of it is free of affect and can be observed objectively (Ashworth, 2008). At the other end is the subjective, interpretative, and constructivist position, where affect is seen as integral and interpretation offers the opportunity to capture the complexity of human *experience* (Smith, Flowers, & Larkin, 2009).

My epistemological position lies within the subjective, interpretative, and constructivist end of the continuum. Specifically, an interpretative (hermeneutics) phenomenological constructivist position. This means that my personal and professional life is influenced by these theories of knowledge: I seek to understand the world and the experience of those I work with (phenomenology), with the belief that individuals construct their reality and that this can be informed, influenced, or determined by their context (constructivism/social constructionism), and that we can seek to understand and make sense of the world in relation to those we come into contact with using interpretations, which may be aided or misunderstood by the perspective of others (hermeneutics).

Interpretative Phenomenological Analysis (IPA), the methodological approach employed for this research, is derived from a similar epistemological position. The approach aims to explore the

research participants' experience of the world, from their own perspective – though “recognises that such an exploration must necessarily implicate the researcher's own view of the world as well as the nature of the interaction between researcher and participant” (Willig, 2008, p.56).

The research questions for this research are influenced by my epistemological position. The primary questions were designed to provide a detailed analysis of palliative care nurses' lived experience of interpersonal challenges with dying patients, and the emotional impact of such challenges. The questions relate to a particular group, and how they make sense and meaning from a particular phenomenon; lending itself well to the IPA approach.

The secondary research question has its roots in psychodynamic psychology, which is an area of interest and importance to me, particularly when interpreting meaning, dynamics, and relational patterns. This interest arose in the context of my clinical psychology doctoral training, and also personal therapy, where psychodynamic thinking was an integral part of understanding people and also myself.

It has been argued that IPA and psychodynamic psychology each represent differing epistemological positions, with IPA providing interpretations from *within* the text, and psychodynamic interpretations from *without* (Smith, Flowers, & Larkin, 2009). Or in other words, IPA is asking “how is this person experiencing and making sense of this phenomenon”, whereas psychodynamic interpretations ask “how do *I* think that person is experiencing this phenomenon, and how can I make sense of that”. However, Kvale (2004) argues in contrast that psychoanalytical knowledge production is congruent with the relational approach of phenomenology, hermeneutics, and social constructionism (p. 277). Indeed, there have been several examples of other studies that have also made explicit use of existing theory in conjunction with IPA (e.g. Partridge (2012), Yusof and Carpenter (2014) and an unpublished doctoral thesis by Dennison (2016)).

I chose to include this secondary research question because I believe it will enable a deeper understanding of a phenomena. Furthermore, IPA accepts that the researcher cannot suspend their own experience from the process of research, and that instead the approach must embrace the reality that the researcher are themselves making sense of the participant making sense of a phenomena. As such, my secondary research question aims to - as much as is consciously possible - intentionally capture this element of the process.

### **Statement of interest**

My interest in this topic is connected to several things, both personal and academic. Above, I have already described my interest in psychodynamic psychology and communicated something of my relationship to this approach originating from my learning as a trainee clinical psychologist, but also from my own personal psychotherapy which has been a journey of rich and meaningful discovery.

My interest in the broad topic of death, and the anxiety that death generates in all of us, is at least in part a product of some of my own tragic losses in recent years. Not just the losses themselves, but also the curious ways that death and loss caused other people and professionals to react. My experiences have been painful at times, but also joyful, and many things in between, and I continue to think about how these experiences influence my life and my work. I believe that one cannot separate life choices such as career, interests, hobbies, and relationships, from their personal experiences and the things that have happened to them. In taking this position and holding this belief, it feels important for me to always wonder what might be happening for me in any given moment or in relation to any particular pursuit. IPA accepts that the researcher cannot be made separate from the research, and thus all the above will be considered carefully throughout the research process.



**Appendix E. Ethical approval from Salomons Ethics Committee**

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**Appendix F. HRA approval letter**

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**Appendix G. Ethical approval of amendments from Salomons Ethics Committee**

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## **Appendix H. Email to palliative care professionals' networks as a means to recruit study participants**

Email subject: Palliative care research project

To whom it may concern

I am a trainee clinical psychologist, working for the NHS, and am in the process of conducting a research project which is interested in the experiences of palliative care staff - particularly in the context of challenging interpersonal experiences with patients.

My project has satisfied ethical standards for my university (Salomons Institute for Applied Psychology, Canterbury Christ Church University).

I am looking to recruit qualified palliative care nurses for participation, who currently work in a palliative context, delivering direct patient care. Participation will involve being interviewed by me with the aim of capturing the experiences of staff in relation to the above. Participation will be voluntary and independent of participants' NHS affiliation.

I would be grateful if this email could be distributed amongst your network of clinicians. Any interested palliative care nurses should contact me directly, at which point I can describe my project in full. Interviews would be via video conference (e.g. skype/zoom) and thus COVID safe.

Warmest wishes

[*researcher name*]

Trainee Clinical Psychologist

Salomons Institute for Applied Psychology  
Lucy Fildes Building, 1 Meadow Road  
Tunbridge Wells  
Kent  
TN1 2YG

## Appendix I. Staff briefing and recruitment prompt sheet

I am in the process of conducting a piece of research that I would like to carry out with palliative care nurses. Participation would involve being interviewed by me. I can say more about this later.

The research is about the experience of being a nurse working in palliative care. Primarily, I am interested in what your experiences are of working in palliative care when encountering a patient who feels quite challenging, and what is the emotional impact of such experiences.

‘Challenging’ can be defined in many ways, and will be different between people. Some of the challenges we may face in such a working context could be when we experience a patient as angry, or when a patient refuses our support. Other challenges with patients might involve their wider family network, or perhaps when seeing someone who is in a lot of pain, or who has unpleasant symptoms. Other challenges could be a patient who reminds us of a loved one, or a patient who is lonely or has difficult personal circumstances, and so on. Because it can mean such different things to different people, I am interested in *your* unique experiences. So, part of the interview will involve thinking more about that.

Palliative care is a specialism which comes with many challenges – the very nature of working with dying patients can be difficult and at times very emotional. Therefore, I am interested in what it feels like for staff when also being confronted with a patient who feels challenging. I am interested in how staff respond to and cope with such situations, and whether this has an emotional impact on them.

Another of the aims of the project is to also think about whether there may be any underlying effects – effects which might not be obvious, but which can be valuable to think about. Some theorists suggest that there can be influences operating at a less-conscious level – especially when facing challenges such as those that might be faced by working in palliative care. A secondary aim of the project will be to tentatively explore this concept.

What I hope is that with your input and your unique perspective, we can learn more about what it is like to work in palliative care. This can have implications for the future when training new staff, and when supporting existing staff. It may also give us a unique perspective on what life is like for patients, but through your eyes. Finally, as research often is, it could also be a motivation for other researchers to look further into this field of research.

If you still feel interested in taking part, or if you want to hear more about the project, I can be contacted via the following means:

- You can ask now whilst we’re on the phone together.
- Email: *[removed from electronic copy]*

## Appendix J. Project information sheet

Faculty of Social and Applied Sciences  
 Clinical Psychology Doctoral Programme  
 Salomons Institute for Applied Psychology  
 Canterbury Christ Church University

### Study title

'Palliative care nurses' experience of interpersonal challenges with dying patients'

### Introduction

Hello. My name is Kyle Boyd and I am a trainee clinical psychologist in the doctoral programme at Canterbury Christ Church University. I would like to invite you to take part in a research study.

This project is being supervised by:

**Prof. Hilary Brown**, Psychotherapist    Salomons Institute for Applied Psychology

**Dr John McGowan**, Clinical Psychologist    Salomons Institute for Applied Psychology

Before you decide whether to take part, it is important that you understand why the research is being conducted and what it would involve for you.

### What is the purpose of the study?

The purpose of the study is to understand how palliative care clinicians experience working with patients who feel challenging. Palliative care is a specialism which comes with many challenges – the very nature of working with dying patients can be difficult and at times very emotional. Therefore, I am interested in what it *feels* like for staff when also being confronted with a patient experienced as challenging. I am interested in how staff respond to and cope with such situations, and whether this has an emotional impact on them. One of the aims of the project is to also think about whether there may be any underlying effects – effects which might not be obvious, but which can be valuable to think about so that we can consider whether additional support or training is needed, or perhaps to acknowledge the value of existing modes of support.

### Why have I been invited?

I am interested in understanding a palliative care clinician's experience, specifically. Working in this capacity, you offer a unique perspective that I would like to learn more about.

### Do I have to take part?

Participation is voluntary, so you do not have to participate if you do not wish to. It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time prior, during, or following interview, without giving a reason. If you wish to withdraw after the interview has taken place, you will have 30 days to notify

me of your wish to withdraw. You can stop being part of the study without giving a reason, but we will keep information about you that we already have.

### **What will happen to me if I take part?**

- I will interview you once, and the interview will last no longer than 90 minutes.
- The questions will cover several areas which are all in some way connected to your experiences of caring for patients who felt (or feels) challenging to you.
- The interview will take place via video conferencing or telephone if you prefer.
- Your participation is anonymous. We will arrange a time to meet which allows you the greatest discretion and comfort.
- I aim to complete the project by December 2020, at which point the findings can be fed back to you if you wish.

### **Expenses and payments**

None applicable.

### **What will I be asked to do?**

Answer as many questions as you are able to, as honestly as you are able to.

### **What are the possible disadvantages and risks of taking part?**

I will be asking questions of a personal nature, which can be difficult for some people. One disadvantage is that my questions might lead you to think about something that feels painful or distressing in some other way. You are not obliged to answer if you do not want to, and I would like to reassure you that you can withdraw at any time without consequence.

If you do find anything that I ask distressing, then there are several options available to ensure you get the support you need, if you feel that you would like support.

### **What are the possible benefits of taking part?**

We cannot know if the study will help you but the information we get from this study will potentially help to improve our understanding of what it is like to work in a palliative care context, and the effects on staff. We hope that it will tell us something new about how to support the staff team and whether there may be additional training needs. It may also reveal that existing support options are working well.

### **What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

### **Will information from or about me from taking part in the study be kept confidential?**

Yes. We will follow ethical guidance from the university and British Psychological Society. All information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

### **Summary of information concerning the protection of your data.**

In this research study we will use information given by you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it or for future research.

We will make sure no-one can work out who you are from the reports we write.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 (**see below**) before making any decision.

## **Part 2**

### **What will happen if I don't want to carry on with the study?**

If you wish to withdraw during the interview, the process will be stopped immediately, without needing to give a reason. Any data collected prior to that point will still be used in the analysis. You are free to discuss any concerns that you have with the researcher at the time of interview or you can discuss with the project supervisors. If you wish to make a complaint, please see below for guidance.

If you wish to withdraw after the interview has taken place, you will have 30 days to notify me of your wish to withdraw. At this point all data will be removed from the study in its entirety and destroyed.

### **What if you have concerns?**

Please do let the lead researcher know if you have experienced any problem and I will do my utmost to resolve your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me, Kyle Boyd, and I will get back to you as soon as possible

### **If you want to make a complaint**

If you are dissatisfied and want to complain formally you can do this by contacting Dr Fergal Jones, Research Director, Salomons Institute for Applied Psychology, email: [fergal.jones@canterbury.ac.uk](mailto:fergal.jones@canterbury.ac.uk) tel: 01227 927070.

### **Will information from or about me from taking part in the study be kept confidential?**

All information collected from or about you during the course of the research will be kept strictly confidential. Below details how your data will be handled.



- You will be assigned a participation code which will be linked to the files associated with your participation. This maintains confidentiality, whilst ensuring ease of reference should you later wish to withdraw.
- Interviews will be audio recorded, before being transferred to an encrypted and password protected storage device. Only the researcher will have access to the raw recording.
- The recording will be transcribed and all identifying information will be anonymised. Pseudonyms will replace any names, and any other identifying information will be masked with careful attention.
- Once transcribed, audio recordings will be destroyed.
- You will receive a copy of your interview transcript and will be invited to review it for accuracy.
- Only authorised persons will have access to the data. Authorised persons include researchers, regulatory authorities, project assessors, and Research & Development audit (for monitoring of the quality of the research)
- Anonymised interview transcriptions will be stored on an encrypted and password protected storage device during the completion of the project, and subsequently held in secure and locked file for 10 years by Canterbury Christ Church University.
- Your data will be analysed along with the interview transcripts from other participants, and themes will be generated. Themes are less reflective of an individual, and more of the researched group and thus anonymity can be further assured.  
The limits of confidentiality
- The only time when I would be obliged to pass on information from you to a third party would be if, because of something you told me, I were to become concerned about your safety or the safety of someone else.  
All participants have the right to check the accuracy of data held about them and correct any errors. You will be invited to review the transcription of your interview to assess the accuracy.

### **What will happen to the results of the research study?**

All interviews will be transcribed and you will have the opportunity to check the transcription for fidelity. All interview transcriptions will go through a thorough analysis, from which themes will be generated. This means that your data will be analysed individually, but then considered with a broader set of themes, which will not solely include your data.

The results of the research study will be fed back into the service, but will never make known those individuals that took part. The research will subsequently be submitted for publication.

Please be reminded that all identifiable information will be anonymised and all reasonable efforts will be taken to protect the confidentiality of participants.

### **Who is organising and funding the research?**

Salomons Institute for Applied Psychology, Canterbury Christ Church University

### **Who has reviewed the study?**

To protect your interests, all research in the NHS is looked at by an independent group of people called a Research Ethics Committee. This study has been reviewed and given favourable opinion by a university ethics panel at Salomons Institute for Applied Psychology, Canterbury Christ Church University.

### **Summary of important information concerning the protection of your data**

#### **How will we use information about you?**

We will need to use information from you for this research project.

This information will include your initials and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

### **What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

### **Where can you find out more about how your information is used?**

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- by asking one of the research team
- by sending an email to [fergal.jones@canterbury.ac.uk](mailto:fergal.jones@canterbury.ac.uk) (Research Director) or
- by ringing us on 01227 927110.

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Primary researcher:

Kyle Boyd

Trainee Clinical Psychologist

Project Supervisors:

Prof Hilary Brown

Salomons Institute for Applied Psychology

Dr John McGowan

Salomons Institute for Applied Psychology

## Appendix K. Consent form

### CONSENT FORM

**Title of Project:** 'Palliative care nurses' experience of interpersonal challenges with dying patients'

**Name of Researcher:** Kyle Boyd

**Contact details:**

Address: Salomons Institute for Applied Psychology  
Lucy Fildes Building, 1 Meadow Road  
Tunbridge Wells, TN1 3YG

Tel: 01227 927070

Email: *Kb695@canterbury.ac.uk*

**Please initial box**

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time prior to, during, or following interview, without giving any reason. (If you wish to withdraw after the interview has taken place, you will have 30 days to notify me of your wish to withdraw. At this point all data will be removed from the study in its entirety and destroyed)
3. I understand that any personal information that I provide to the researchers will be kept strictly confidential
4. I agree to take part in the above study.
5. I agree to be recorded, understanding that audio files will be destroyed once anonymised and transcribed


Name of Participant:	Date:	Signature:
Name of person taking consent ( <i>if different from researcher</i> )	Date:	Signature:
Researcher:	Date:	Signature:

Copies: 1 for participant 1 for researcher

## Appendix L. Interview schedule

Interview time: 60-90 minutes

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### Interviewer prompts (pre-interview)

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1. Thank the interviewee for their time.
2. Describe researcher background, current role and title of research.
3. Refer to Participant Information Sheet and Informed Consent Form to reiterate:
  - Length of interview
  - Can opt out at any time during interview (and up to one month from date of interview)
  - Participant does not have to answer questions they are unhappy with
  - Confidentiality and anonymity
  - A debrief at the end (to answer any questions and check how they are feeling)
4. Mention that the interview is like a one-sided conversation – researcher will say very little compared to them.
5. Answer any questions on the research process.
6. Reassure that if any notes are taken, it is as a memory prompt and will be destroyed soon after.
7. Ensure that a signed copy of informed consent sheet is given to participant.
8. Reminder that we will broadly discuss:
  - Your experiences of challenging interactions with dying patients
  - How you respond to such experiences
  - How you make sense of these experiences
  - How you feel when you experience a challenging interaction
  - How you process and manage emotions that may be provoked in you
9. The term “challenging interaction” will mean different things to different people. We are interested in what *you* find challenging and this will be explored with you. Broadly we are looking to understand any perceptions that you may have regarding the more negative aspects of interactions with dying patients.
10. Find out basic background information (age, ethnicity, qualifications and experience).
11. Turn on dictaphone.

## **Appendix M. Audit process**

The following documents were reviewed by my two lead supervisors during the research process for the purposes of rigour and accountability:

1. Two un-annotated transcripts
2. Two completed transcripts with initial notes
3. An Excel spreadsheet demonstrating the process of gathering codes, and placing them into emerging themes for each individual participant. All codes were supported by corresponding quotes from participants
4. An Excel spreadsheet demonstrating the process of gathering emergent themes into sub-themes which adequately capture the experiences *across* participants
5. Results section with final sub- and superordinate themes, together with supporting quotes from transcripts

**Appendix N: Sample transcript**

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### Appendix O: Example of emergent theme development for PCN 3

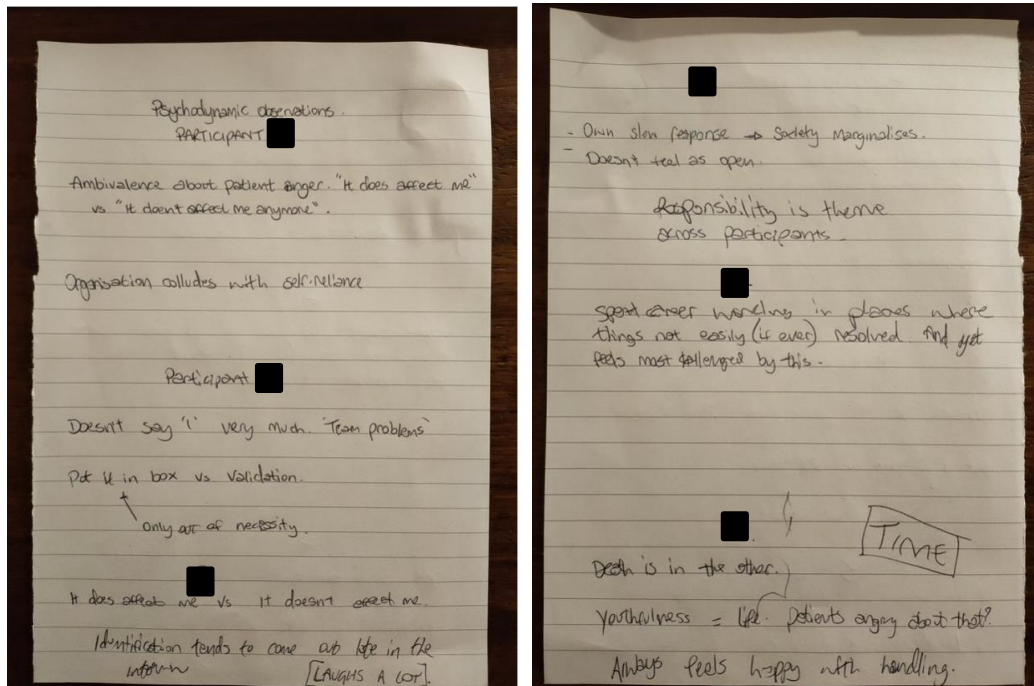
Table 4: A table to illustrate theme development for PCN3

<b>Emergent themes</b>	<b>Responsibility and control</b>	<b>The challenge of unaccepted care</b>	<b>The personal and the professional</b>	<b>The way I am affected</b>	<b>The good death</b>	<b>Importance of support and validation</b>	<b>Trying hard to meet the patient's needs</b>
<b>Codes</b>	Challenging when feeling responsibility for person's care	Challenging when patient won't accept help offered	Flippant use of language	Laughing when uncomfortable	Challenging when feeling responsibility for person's care	Challenging when feeling responsibility for person's care	Try to meet patient where they're at
	It's not just me	Challenging when patient does not respond to help offered	Personal identity	Flippant use of language	Try to meet patient where they're at	Challenging when patient does not respond to help offered	Rational vs emotional
	Rational vs emotional	It's not just me	Try to meet patient where they're at	Rational vs emotional	Challenging when someone is dying and hasn't been able to prepare	It's not just me	Don't accept responsibility where you don't have authority
	Don't accept responsibility where you don't have authority	Rational vs emotional	Not a challenge any more	Experience has helped to manage challenging situations	If you're dying, I've got to tolerate rudeness	Lack of professional reward	Patient gratitude or affirmation
	Need to adjust own expectations	Need to adjust own expectations	Lack of professional reward	Identification	Feel skilled at...	Personal characteristics contribute to experience of challenges	The importance of 'being with'
	Challenging when someone is dying and hasn't been able to prepare	Patient history of mental health difficulty is challenging	Identification	Provoked feelings of frustration	Guilt	Importance of team support	Sense of organisational pressure

Provoked feelings of frustration	My solutions are rejected	Don't show the patient your feelings	Sense of organisational pressure	Challenging when dying trajectory is not clear	Patient gratitude or affirmation	If you're dying, I've got to tolerate rudeness
Sense of organisational pressure	Challenges are positive because you learn from them	Professional disconnection	Felt alone	People dying are saints	Challenges are positive because you learn from them	Challenging when patient is demanding
A patient's history influences dying experience	Challenging when patient is demanding	Important to differentiate between personal and professional identities	Challenging when patient is demanding		Shared experience amongst nurses helps to contain	Do it properly, do it once
Temptation to treat patients like children	Challenging when witnessing self-sabotage	We rarely connect to own mortality	Guilt		Enormous relief when she felt support of colleague	Challenging when witnessing self-sabotage
Take control		Working with the dying is positive	Thinking about challenges provokes live emotional response		Supervision is for difficult stuff	Impatience
Need to do the right thing		We absorb emotion and need to wring it out	The work is rarely personally affecting			Need to do the right thing
			Unable to disconnect			



## Appendix P. Sample of note-taking process for psychodynamic interpretations



Psychodynamic notes	Participant quote
Identification	Yeah. I think that's true. I think, um, I think there are some patients you identify with. Probably less so than I did. I think when you're younger and you have a younger person, I think when you... I'm in my 50s now and I think you have more people you see of your peers, your age group. It becomes less unusual. I think when you're in your 30s and you have somebody in their 20s and 30s... I mean it's still horrible now, don't get me wrong. It really feels all wrong to see somebody dying and their in their 20s and 30s, but it's less surprising and so I think there's less identification. And, and I think identification is... is less... I don't identify as much as I used to. And I don't know why that is.
Projection	I'm thinking of a young woman that I'm seeing now. Even on Friday, her son was very angry and said "I don't want anything to do with the likes of you" essentially thinking that his mum is dying and somehow, you know, we're seen as part of that process.
Denial	that would have felt really personal I think 'oh I'm really failing you if you've come away with that impression'. And when I checked it back with her she said "no I don't really think you're trying to kill me, I'm just having a melt-down" and I think I said "and I think you're right to have a melt-down". So, again it felt about her and not about me. And I think that's what shifts with experience
Rationalisation	I didn't find his... I found his anger completely understandable. And it didn't make me feel... I just felt really sad for him.
Transference	But again, with reflection I thought that is saying something about him, and not about the way I handled that. Although I could've... handled it differently – you know I always think if something goes... because he was cross, I... I think you always have to reflect on how you've handled things and that's challenging too.
Transference	I think you have to be open and, and um, translating and interpreting emotions coming your way and checking if that's right. And then, and this is the bit I don't always do, is in the moment I can't think 'so you're picking this up, what's it doing to you [participant name]?' Because I don't think you always can before the things you're thinking about, umm... and I think that is the thing that you have to try and learn is 'I'm taking this in' and checking in with yourself.
Denial and/or repression	I often use that analogy with colleagues, you know when they're really... they sometimes do get overwhelmed with a situation that's really sad. And it's that sucking in of emotions over time, like little sponges, aren't we? And... if you don't wring that sponge out then you can't take any more in, can you? I'm thinking of a husband of a wife who was, she was a nurse, there was a bit of identification maybe, with her.
	And, and I think identification is... is less... I don't identify as much as I used to. And I don't know why that is.
	So, people can criticise me for not having everybody ticked and tick-boxed. But actually I'm not going to push people to do thing they don't want to do. But I think some of those tasks, like prescribing, like writing out resuscitation forms, like... they can be quite protective and stop you getting in to the... you know, 'how is it actually feeling here for you?' 'what's going on?'

## Appendix Q: Sub-theme development by grouping emergent themes

Key (clockwise from bottom left)

YELLOW = Validation and containment

FUSCIA = Support and supervision

BLACK = Professional issues

LIGHT PURPLE = Palliative care is personal

PINK = About me/ the reason I'm here

RED = The effect of affect

LIGHT GREEN = Defences, self-protection, and coping

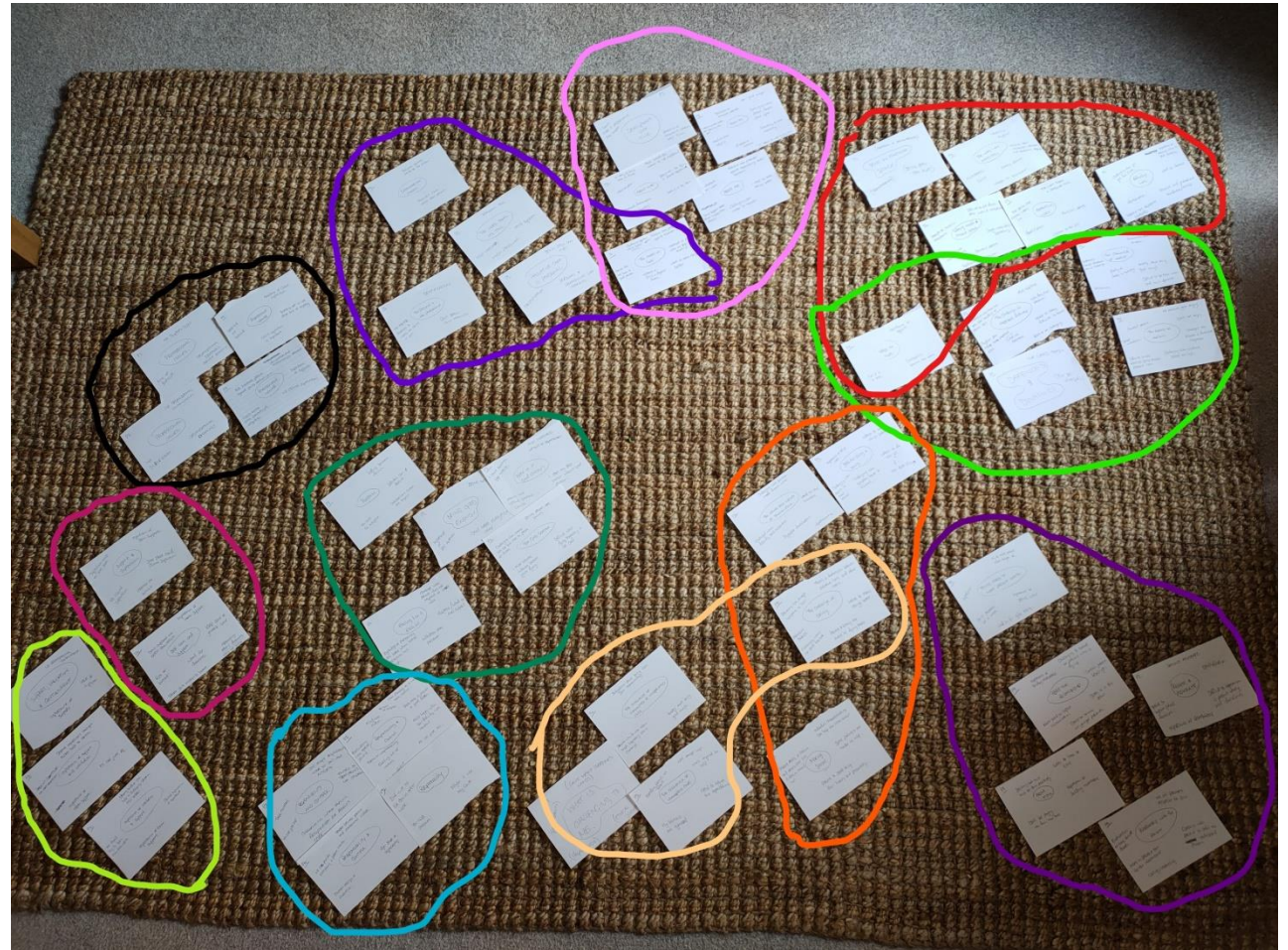
DARK PURPLE = Relationship with the patient

ORANGE = Between 'fixing' and 'being'

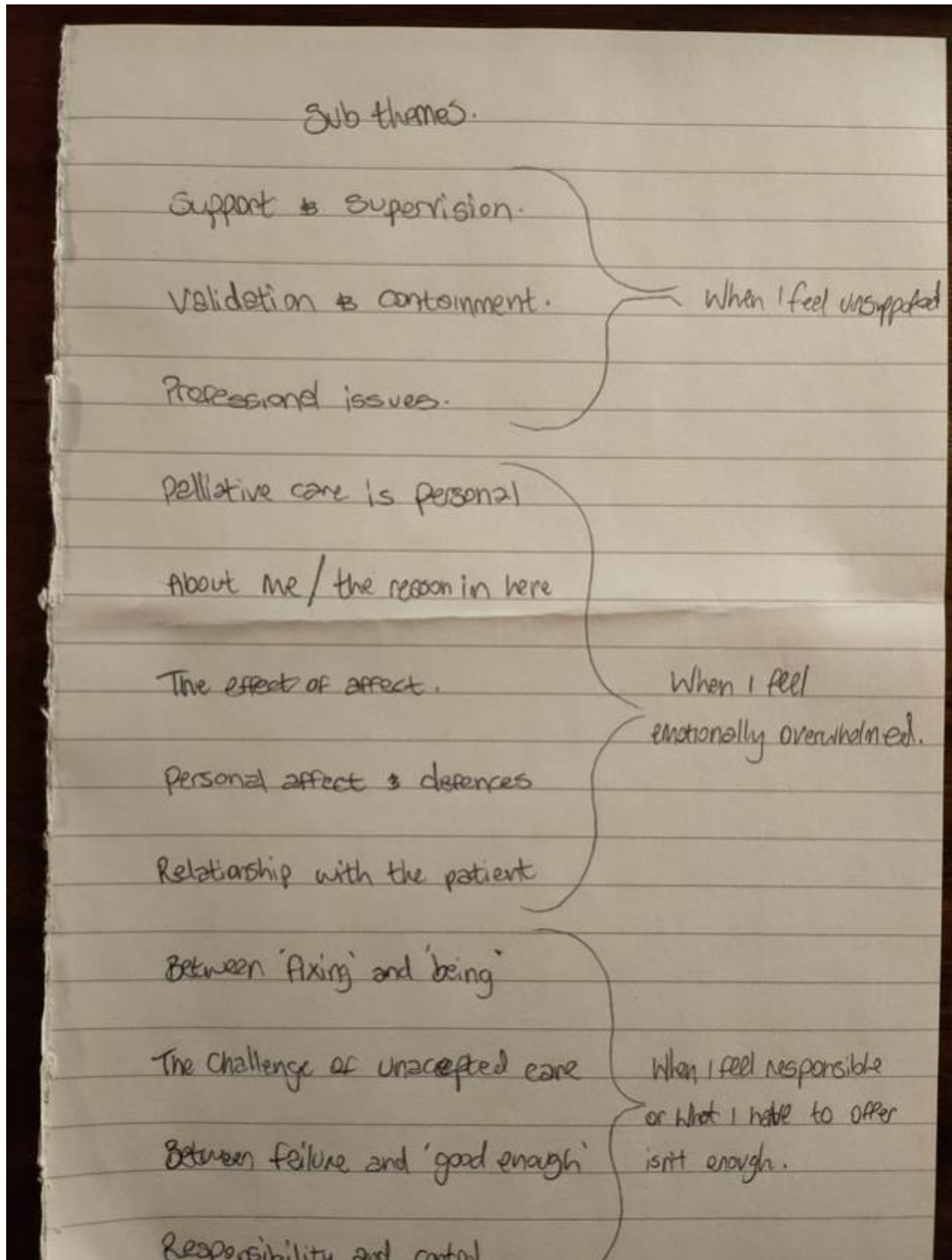
PEACH = The challenge of unaccepted care

DARK GREEN = Between failure and good enough

BLUE = Responsibility and control



## Appendix R. Superordinate theme development notes



## Appendix S. Excerpts from research diary

<b>Date</b>	<b>Entry</b>
02 Jan 2018	Agreed with Monika that she would be my supervisor for a project which is interested in dementia screening tools. It's a quantitative project, and seems like it's ready to go.
01 Feb 2018	I need to use a programme called E-Prime and will have to learn to do a bit of programming with it in order to develop a protocol for patients with Mild Cognitive Impairment. Still trying to get my head around this field of research, but this project is feeling rather bigger than I first anticipated.
15 Feb 2018	I've now been linked up with an external supervisor – Dr Reinhard Gus. I know him already from a previous role which I hope with ease things along. Will be meeting him in the coming weeks to discuss.
15 May 2018	I submitted my draft research proposal to Monika and she wasn't keen. In fairness I based it quite closely on a proposal that she submitted about a concurrent project which is very similar. In any case, I will have to get a submission extension and get it redone.
11 June 2018	I have a new proposal which is much better now. However... and this is a big 'however'. Monika has left her role rather abruptly and so I'm not sure what's going to happen now. This was essentially her project.
20 June 2018	I've ditched the project. It appears it was too big and niche for any other researcher to support me. To be honest it feels like a relief as I was slowly discovering that this project is not for me. I'm quite anxious about what happens next, but I'll arrange a meeting to discuss with my manager and go from there.
10 Aug 2018	I have a new supervisor – Hilary Brown. I was pointed in her direction after highlighting some of my own interests. As morbid as it sounds, we'll be doing a project which is connected in some way to death and death anxiety. Not sure how it's going to go, but I feel a little more excited by this than I did about the previous project.
19 Sept 2018	I now have a November date for my MRP proposal submission. My project is going to be looking at the effect that working in palliative care has on nurses – with particular interest in psychodynamics.
01 Oct 2018	I met with my external supervisor today at Guy's hospital (Dr Sue Smith) along with the palliative care consultant. They are willing to support me with the project and said that once things are approved (ethics etc) I can get to work collecting data from the team who are split across the Guy's site and the St Thomas' site. Feels like this is coming together now.
22 Oct 2018	My manager John McGowan has agreed to come alongside Hilary in being my 'first' supervisor.
2 Nov 2018	Submitted the 'bare bones' of a proposal. Still work to do in getting supporting materials written. Salomons are being supportive with how long this is taking to get organised, thankfully!
19 Nov 2018	I attended a talk this evening on the subject of 'death talk'. Very interesting.
18 Jan 2019	Frustratingly, I've still not been able to submit my completed proposal. Life seems to be throwing all sorts in the way of me... and perhaps I'm also somehow allowing life to throw things in the way.
04 Mar 2019	My daughter was born!!
19 Jul 2019	Finally had my proposal approved! It took me a very long time to get this together, but there now feels like there is some momentum. Now for ethics.
23 Aug 2019	I met with Hilary today. She has expressed to me that she intends to be a bit of a nagging supervisor in order to keep things moving. I'm quite overwhelmed at the prospect of doing this research, to be honest. I feel rather out of my depth. Thankful that she seems to have recognised that something in me is slowing this process down and seems to want to help me to keep going. Preparation for ethics submissions continue.
17 Dec 2019	I finally have ethical approval!! What a big day. Just need to sort out IRAS – which is still don't feel a have a full grasp of. Nevertheless, this feels like the final hoop to jump and I can start data collection!
17 Feb 2020	IRAS is all done!! Now to book in to meet the staff at Guy's & St Thomas'
10 May 2020	Owing to COVID my project had to be put on hold. I've been given a deferral which

- has given me the time I need to wait this situation out. That said, I'm having some difficulty in making contact with the staff at Guy's hospital. I understand the pandemic is having a huge impact on everything at the moment, but it feels really unclear when I am going to be able to get in to collect my data. I'm hoping they'll consider allowing staff to be interviewed via video call.
- 14 Aug 2020 Just received confirmation that I cannot collect data from Guy's. After resubmitting an ethics form amendment which allows me to recruit nurses via other means, I can go ahead and find participants independently of NHS affiliation. It seems that Dr Sue Smith has stopped replying to my emails... I suppose it'll just have to carry on with only my other two supervisors.
- 25 Aug 2020 Conducted my first interviews today!!! It was really great and was done via Zoom. I feel it went so well and was very interesting to hear about the experiences of the two nurses that I interviewed. Very very pleased!
- 08 Oct 2020 Final interview done. I managed to recruit seven participants, which isn't as many as I'd hoped, but it is more than the IPA book suggests. It will have to be enough because I need to write this up now. Deadline is December and I just moved across the country and just started a new job!
- Dec 2020 Sadly my father became unwell and in an interesting and very difficult turn of fate, I had to attend to his palliative care needs. He sadly died on 11<sup>th</sup> December and now I am in Northern Ireland trying to organise a funeral. I'm utterly devastated and exhausted from the travelling back and forth from Wales. Salomons have allowed me to defer to April which I am deeply thankful for.
- 22 Feb 2021 I've finished the Part A of my project. Having written it over the last few weeks, I was able to get some drafts looked at and worked on, and now I can finally say that it is finished. Still a way to go and it feels quite big in my mind, but I have also made some good progress with the intro and method sections of the Part B.
- 05 Apr 2021 I have two weeks now to work on the Part B. I will be focusing on the analysis, which I hope will take a couple of days, allowing me to get the rest written up and checked in time for the deadline at the end of next week.
- 13 Apr 2021 The analysis has taken much longer than I had anticipated. I realise now quite how naïve it was to think I would get it done in a couple of days. My plan went out of the window and I am still wading through the data. I hope that my rigor will serve me well when it comes to writing this up.
- 16 Apr 2021 Today is deadline day and I've had to request a two-week extension (30/4/21). I'm feeling *very* stressed about this now. I don't trust my own timeline and plan, and worry I'm not going to make it. I will keep going and just use whatever time I can find to work on it.
- 21 Apr 2021 Analysis is almost done and I have been working on some of the important peripheral items, such as appendices and tables/figures. I feel like it's coming together but it is getting to the point where it is keeping me up at night. There's something about this project which I am finding so incredibly difficult to overcome. I've sent over a few draft items to John and Hilary for review and hope that they'll find them satisfactory.
- 30 Apr 2021 I'm finally finished. It's 12:30pm and I have an hour and a half to get my appendices sorted out. I've been working without a break since around 3pm yesterday afternoon

## **Appendix T. Closing report to Ethics Committee**

### **Letter for the Salomons Ethics Committee upon the completion of Kyle Boyd's Major Research Project.**

To whom it may concern,

I am writing to confirm my completion of the major research project titled: Palliative care nurses' experience of interpersonal challenges with dying patients: An interpretative phenomenological analysis and psychodynamic exploration.

#### **How did it go?**

In summary, the project was fraught with challenges from start to finish. I experienced my first project falling through, then some difficulty in finding a supervisor, difficulty in collecting data, COVID completely interrupted proceedings and ultimately led to the need for an alternative recruitment strategy, and then my father sadly passed away which meant that I had to request a second deferment.

However, I got there in the end! I don't feel as satisfied with it as I might, because I didn't allow the time for supervisors to read drafts of every section of the report, and I didn't allow myself the time to work through the write-up in a way which might have reassured me of its quality. That said, I think I have produced an interesting and hopefully a good enough piece of work which may provoke thoughtfulness, and perhaps change, in the contexts from which it was developed.

Once I had ethical approval to recruit independently of the NHS, I had no further significant interruptions in the research process. My participants were interesting, open, and taught me a lot about their experience of working in a powerfully affecting environment. They spoke movingly, honestly, and I felt like with each of them I was able to develop a helpful rapport for the process of qualitative data collection.

I had to take care of my father during his final weeks after a very short illness, giving me a very personal experience of end-of-life care. I think that this made some of the analysis difficult for me and I chose to give keen attention to my own self-care.

I'm glad that this project is now over – which is a curious thing to feel given the subject material. It's similar to the relief I felt once my father had died, and I suspect this mirrors part of the experience of staff when witnessing the dying process. Death really is unbearable, just as the literature suggests... but it is also life-affirming, and I have been profoundly moved by the stories and experiences of those who took part in this project.

## Summary

I interviewed seven participants and analysed the data using Interpretative Phenomenological Analysis and psychodynamic exploration. Three superordinate themes emerged and I hope I gave the themes adequate thought and space in the results and discussion sections, respectively. I think if I could go again, I would think more carefully about the methodology. Including the psychodynamic exploration was a challenge with the limited word-count, and with more space I could have given better attention to the very interesting unconscious content which emerged in the data.

I feel excited about the viva, but also nervous. Over the course of this project and the training as a whole, I have come to learn that there are times when my work doesn't quite satisfy the assessment criteria, whilst at other times I satisfy it with tremendous comprehension. I hope that this project will fall within the latter category, but I am anxious that it might not. I am aware of some areas which might benefit for a little more time and thought, but I keenly anticipate the feedback of my assessors.

Yours faithfully

Kyle Boyd