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What is ‘Moral Distress’ in Nursing and How Should We Respond to It?

Miss Georgina Morley

A dissertation submitted to the University of Bristol in
accordance with the requirements for award of the degree
of Doctor of Philosophy in the Faculty of Health Sciences.

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Abstract

What is ‘moral distress’ in nursing and how should we respond to it?

Within this thesis, I explore the concept of ‘moral distress’ in nursing using both theoretical and empirical methods. Using a feminist empirical bioethics methodology, I explore issues of voice, power, responsibility and relationships and the way in which these impact nurses’ experiences of moral distress.

I present qualitative data from interviews with 21 critical care nurses in which they describe different moral events that caused them to feel the various emotions of ‘distress’. Using the empirical findings and tort law, I suggest causal criteria which explains the causal story between the moral event and distress, determining whether one’s distress ought to be regarded as *moral* distress. I argue for a broader conceptualisation of moral distress based upon the empirical findings and I provide normative reasons why we ought to accept this broader understanding. I argue that due to the complexity of clinical-ethical decision-making and prognostication that moral distress ought to be divorced from ‘knowledge of the right thing’, that this broader definition may encourage moral dialogue between healthcare professionals, and that to disregard these experiences as moral distress deprives these individuals of the tools to make sense of their own moral experiences.

I construct a moral distress model which captures the definition of moral distress, the compounding factors that exacerbate/mitigate moral events, responses to moral distress and the interaction of moral distress to other related concepts. Finally, I provide recommendations for ways we can respond to moral distress in clinical practice and policy, and possible areas for further research.

Dedication and Acknowledgments

Overwhelmingly, I have enjoyed my PhD journey and feel I have gained so much from this process and grown as a person, and as a nurse. So much of my identity and purpose in life is in my professional work and I am grateful to have been privileged enough to have this academic challenge.

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Foremost, I must thank Tommy for yet again supporting me with unwavering patience and love. Whenever I lacked confidence and was full of self-doubt, he was there reminding me of his confidence in me. He has listened to all my ramblings and musings, all my presentations and many of my draft chapters without grumbling (too much). I could not have done it without him.

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Thank-you to my colleagues at Barts Heart Centre, Barts NHS Trust - whose work I admire everyday.

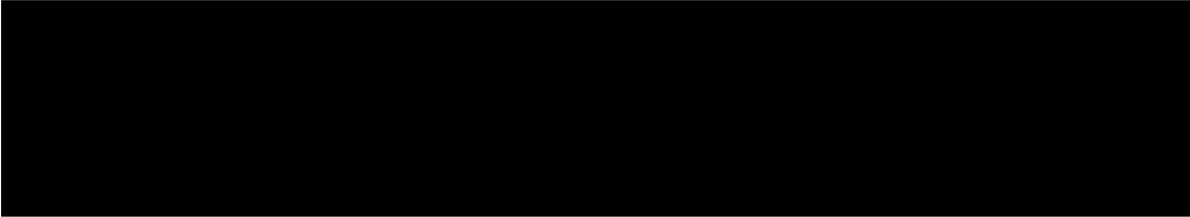
To all nurses, I hope that you continue to find meaning and purpose in your work. It takes great skill to be a compassionate, empathetic, considerate, courageous and knowledgeable nurse. Many of my colleagues achieve this everyday of their working lives. They set aside their own problems, their own loneliness, stress and fear to care for individuals during their most vulnerable moments in life. I am in awe of each nurse who continues in our profession. I am incredibly proud to be a nurse and to have worked alongside you. You all drove me to complete this thesis and to continue the fight for our profession.

Finally, my thanks to the Wellcome Trust for funding this project and the associated public engagement events. I quite literally could not have done this without their financial support. I have tried to represent you to the best of my ability.

“I don’t know, I felt the moment was big but I don’t know, it’s only a small thing isn’t it, switching the pump off? So, yeah it was strange because it felt very big but it was a tiny action.” (Amelia)

Author's Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's *Regulations and Code of Practice for Research Degree Programmes* and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.



List of work published in connection with this project:

Peer-reviewed journals:

- 1) Morley, G. (2018) What is “moral distress” in nursing? How, can and should we respond to it? *Journal of Clinical Nursing* (editorial) Online First. DOI:0.1111/jocn.14332
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Morley and Ives both contributed to conception of the work, drafting and critical revisions of the article. Morley and Ives both approved the final version to be published.
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This published paper is a condensed version of chapter 3 (literature review). Morley contributed to design of work, conducted the literature search, reviewed all articles for inclusion/exclusion, conducted initial data extraction, drafting and critical revision of the article. Ives contributed to design of the work, drafting and critical revision. Bradbury-Jones contributed to drafting and critical revision. Irvine contributed to design of the work and critical revision. All authors approved the final version to be published.
- 4) Morley, G. (2016) Perspective: The Moral Distress Debate. *Journal of Research in Nursing*, 21 (7) 570-575. DOI: 10.1177/1744987116666701
In this paper, I report on the public engagement event that was held in year one of the project. Morley conceived of the work, drafting and critical revisions. The final version was approved by the speakers who engaged in the debate.

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- 2) Morley, G. Ives, J. Bradbury-Jones, C. Moral Distress in End-of-Life Care (in press) in Emmerich, N. Gordijn, B. Mallia, P. (eds.) *Contemporary European Perspectives on the Ethics of End-of-Life*, Springer (Philosophy and Medicine series) (Peer-reviewed)
Morley contributed to design of work, data collection, data analysis and interpretation, drafting the article and critical revision. Ives and Bradbury-Jones contributed to design of work, data interpretation, drafting the article and critical revision. All authors approved the final version which is currently under peer-review.

Other publications:

- 1) Morley, G. ‘Our response to moral distress is shaped by how we define it’ (Sept 2017) *Nursing Times*, opinion section

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List of abbreviations used:

AACN	American Association of Critical-Care Nurses
CF	Compassion Fatigue
ECMO	Extracorporeal Membrane Oxygenation
EEQ	Ethical Environment Questionnaire
HDU	High Dependency Unit
HECS	Hospital Ethical Climate Scale
ICU/ITU	Intensive Care Unit/ Intensive Therapy Unit
MDS	Moral Distress Scale
MDS-R	Moral Distress Scale- Revised
NHS	National Health Service
NMC	Nursing and Midwifery Council
PND	Prenatal diagnosis
PQR	Phenomenology-as-qualitative-research
UK	United Kingdom
US	United States

CHAPTER 1: INTRODUCTION

1.1 Overview

The aim of this empirical bioethics project was to explore the concept of ‘moral distress’ in nursing in the United Kingdom (UK) using both theoretical and empirical methods. The overarching aim was to develop a contextually sensitive conceptualisation of moral distress relevant to nursing in the UK, and to consider how it should be responded to. Theoretical exploration of the concept was broad whilst the focus of the empirical work was on the experiences of nurses working in critical care. This is not to say that ethical issues do not occur in other areas of healthcare but rather due to the complex nature of the critical care environment, the availability of life-sustaining and life-prolonging technology, and that many patients lack the capacity to make decision for themselves, ethical issues occur frequently. This context was therefore deemed likely to provide rich data that could lead to meaningful lessons for nursing practice.

In this chapter, I introduce the clinical context of nursing in critical care and the concept of moral distress. Discussion of moral distress will remain brief because in chapter 3, I present an in-depth review of the moral distress literature. I also provide a brief overview of the methods used to conduct this project and the structure of this thesis in Table 1 (p.20).

1.2 Setting the Scene

Nurses must be registered with their regulating body, the Nursing and Midwifery Council (NMC) to practice in the UK. The NMC lay out the professional standards nurses must uphold in their twenty-page document called ‘The Code: Professional standards of practice and behaviour for nurses and midwives’ (NMC, 2015a). Working in partnership with other healthcare professionals, nurses are charged with the responsibility of caring for the physical, social and psychological needs of patients (NMC, 2015a). Nursing is therefore recognised as an inherently moral profession (Corley, 2002; Austin, 2012).

Nurses often work in busy clinical environments and in the case of critical care, patients are often extremely unwell. ‘Critical care’ refers to an acute care area where patients in need of continuous support or monitoring are cared for. The term ‘critical care’ is used to refer to either high dependency unit (HDU), an area for level 2 patients or an intensive care unit/ intensive therapy unit (ICU/ITU) for level 3 patients. Level 2 patients require continuous support or monitoring of one organ system whilst level 3 patients require continuous support of one or more organ system, or advanced respiratory support such as invasive ventilation (Intensive Care Society, 2008). Within this thesis, I use ICU/ITU interchangeably to mean critical care.

ICU nurses require ongoing education and specialist training in order to safely and effectively provide the advanced levels of care required, therefore many nurses working in ICU have completed at minimum a specialist internal critical

care training course, with the expectation they eventually complete a post registration qualification in critical care (British Association of Critical Care Nurses, 2009, revised 2010). Due to the acuity of the patients, it is recommended that in HDU there is a nurse to patient ratio of 1:2 and in ICU this is 1:1.

ICU is a challenging place to work as patients are critically unwell, family members are stressed and anxious, and nurses are required to be technically skilled to maintain and monitor the machines that are artificially sustaining patients' organs, and to be emotionally skilled to communicate with and care for patients and families. Patients are often at the edge of life and may suffer acute deteriorations such as respiratory or cardiac arrests which require aggressive treatments to sustain organ dysfunction, or they may be transitioning to palliative care measures. Therefore, difficult ethical questions frequently occur in ICU regarding treatment decisions, best interests, quality of life and resource allocation. The ethical issues are rich, various and complex and it is likely due to the ethical complexity of ICU that much of the current research regarding moral distress has occurred in this setting.

1.3 A Brief Introduction to Moral Distress

The American philosopher, Jameton (1984) first introduced the concept of moral distress to the nursing literature, and stated that:

“Moral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.” (p.6)

Since Jameton (1984) provided this definition of moral distress, quantitative tools and scales have been developed to test and measure moral distress, qualitative studies have provided experiential accounts of moral distress amongst nurses and other healthcare professionals, and more recently within the theoretical literature, exploration of the concept itself has occurred. Broadly speaking, two groups of scholars have emerged: those that agree with Jameton's 'narrow definition' (as Fourie (2015) has coined it), and those that argue Jameton's definition is insufficient and needs to be broadened (Campbell et al., 2016). Continued debate and seeming fascination with the concept has meant that research concerning moral distress has exploded in recent years. In a review from Lamiani et al. (2015) a 52% increase in publications since 2011 was reported, of which 71% of these focused on moral distress in nursing. Since then, there have also been several special issues in high impact journals, for example in 2012, there was a special issue in HEC Forum in which the authors aimed to develop an agenda for action on moral distress in healthcare (Pauly et al., 2012); in 2015, Nursing Ethics marked the 30th anniversary of the term; in 2016, the American Journal of Bioethics published a target article by Campbell et al. (2016) who argued for a broader understanding of moral distress; and in 2017, the American Medical Association Journal of Ethics produced a special issue on moral distress and medicine.

Although many authors of these studies disagree about the meaning of the term, they do seem to agree that the moral distress they have explored or measured has deleterious effects upon those who experience it, and this has cemented its

significance as a problem within healthcare. Moral distress has been found to affect nurses personally and professionally. Professionally, moral distress is thought to cause clinicians to withdraw from the bedside, avoid patient contact, and lose capacity to care, and ultimately moral distress is reported to be an additional factor for nurses to leave their place of employment, and the profession altogether (Helft et al., 2009, Rushton, 2006). Researchers have also emphasised the personal effects of moral distress as causing anger, frustration, guilt, loss of self-worth, depression, nightmares, sorrow, anxiety, misery, dread and anguish (Corley, 2002). When we consider the implications of this for a workforce that is already struggling and shrinking, then the issue of moral distress is indeed significant. Data published recently from the NMC showed that for the first time since 2013, more nurses and midwives left the profession than joined it, and two of the most cited reasons for leaving the register were working conditions – specifically poor staffing levels and high workloads – and disillusionment with the quality of care that nurses reported feeling able to provide (NMC, 2017).

There remains, however, a lack of empirical research within the UK, and consequently it is not known whether and to what extent moral distress affects nurses working in the National Health Service (NHS). Despite the increasing number of studies exploring moral distress, very few of these are within a UK context. The lack of consensus regarding how we ought to define moral distress, the lack of empirical work in the UK and my own experiences of moral distress motivated this project. The overarching methodology of this thesis is Feminist Empirical Bioethics, which combines empirical and conceptual methods to

produce contextually-sensitive normative recommendations. I will not go into any further depth here as I discuss this methodology in chapter 2. There were two aims of this project:

Aims:

Primary aim: To develop a theoretically robust conceptualisation of moral distress that is meaningful in the context of UK nursing.

Secondary aim: To develop recommendations for how moral distress ought to be conceptualised, recognised and responded to in a UK nursing context.

The primary aim was met by answering the following research questions using theoretical and empirical methods:

- How is moral distress defined in the theoretical and healthcare literature?
- How is moral distress experienced by critical care nurses in the UK and how does it affect them?

The secondary aim was met by answering the following research question:

- In light of these experiences, how should we define moral distress?
- In light of these experiences, how should we respond to moral distress?

Objectives:

The primary aim was met by addressing the following objectives:

- (i) Carrying out a systematic literature review and formulating a plausible working definition of moral distress.
- (ii) Using face-to-face, semi-structured interviews to obtain an in-depth understanding of UK nurses' experiences of moral distress, what they perceive to be causes of moral distress, how they feel it affects them, and how they can be supported.

The secondary aim was met by addressing the following objectives:

- (iii) Refining the working definition of moral distress formulated in meeting objective (i), informed by the empirical findings generated through meeting objective (ii).
- (iv) Conducting an ethical analysis that considers the most appropriate way to respond to moral distress in a UK nursing context.

Using a combination of approaches from the disciplines of nursing and bioethics, I carried out a systematic review of the literature. The review method was systematic whilst remaining sensitive to the need for integration of conceptual and philosophical literature. A seven-step process suggested by Strech et al. (2008) guided formulation of the search question, the literature search and relevance assessment; whilst the method of 'narrative synthesis' directed critical appraisal, data extraction and methods for exploring relationships between studies (Popay et al., 2006). From the findings, I

postulated a plausible working definition of moral distress.

Following the literature review, I carried out face-to-face, semi-structured interviews with critical care nurses at two NHS specialist trauma hospitals in the UK. These interviews were guided by the empirical method of Feminist Interpretive Phenomenology to gain an in-depth understanding of nurses' experiences of moral distress, their perception of the causes of moral distress, how they feel it affects them, and how they can be supported. These empirical findings provided the 'encounters with experience' that were used to further inform the conceptualisation of moral distress and guided ethical analysis regarding how we should respond to moral distress (Ives, 2008).

Rushton (2006) argues that defining and addressing moral distress is pivotal to developing an ethical practice environment; Hamric (2012) emphasises the need for consistency in defining moral distress, stating that a lack of unity has further complicated attempts to generalise findings, and Corley (2002) has called for the need to develop international research on moral distress to inform policy, practice and education. In line with these calls, I conducted an exploration of the phenomenon of moral distress in a UK setting in order to propose a definition that could be accepted within the nursing and healthcare literature to build a foundation for further exploration of moral distress within the UK nursing context.

Table 1: Structure of Thesis

Chapter Number	Title	Content
Chapter 1	Introduction	An introduction to the critical care setting and the concept of moral distress. Setting out the aims and objectives of the project.
Chapter 2	Methodology	Explanation and justification of the chosen methodology, epistemology and empirical bioethics method.
Chapter 3	Literature Review	Beginning of the inquiry into moral distress through systematically searching and reviewing the moral distress literature.
Chapter 4	Empirical Methods	Description and justification of the empirical method used to collect the empirical data and how it coheres with the methodology, epistemology and empirical bioethics method.
Chapter 5	Empirical Results: Moral Distress	Presentation of the empirical data, my interpretation of the data and how it informs the concept of moral distress.
Chapter 6	Empirical Results: Compounding Factors	Presentation of the empirical data, my interpretation of the data and the ways these additional factors impact participants experiences of moral distress.
Chapter 7	Reflexive Balancing	Challenges to the suggested definition of moral distress and ways to overcome them. Presentation of the 'Moral Distress Model' and responses to moral distress.
Chapter 8	Recommendations	Recommendations for future practice, policy, research and education.
Chapter 9	Conclusion	A brief summary of the project and conclusions drawn.

CHAPTER 2: METHODOLOGY

2.1 Overview

The methodology for this project was complex as it required the combination of different disciplines (nursing and bioethics) and different methodologies (empirical and theoretical) to combine empirical data with ethical theory to inform conceptual development of moral distress, and to provide normative recommendations about how we ought to respond to it. I have therefore divided the methodology and empirical methods into two chapters. In this chapter, I will discuss the theoretical underpinning of this project: feminist bioethics, and a moral epistemology which is often used to underpin this approach and is accepted by feminist philosophers working within feminist bioethics (Scully, 2009; Walker, 2009; Verkerk and Lindemann, 2012). I then discuss the ways in which empirical data can be used within feminist bioethics to provide ‘encounters with experience’ that are used to help ground one’s ethical analysis in real-world experience (Ives, 2008). Following Scully (2017), I coin this ‘feminist empirical bioethics’ as I will be combining empirical data with feminist ethical theory. In chapter 4, I discuss the empirical methodology (feminist interpretive phenomenology) used to gather the empirical data.

The introduction of empirical data into bioethics, or the ‘empirical turn’ (Borry et al., 2005) requires the use of ‘facts’ (empirical data) to inform ‘values’ (ethical theory/normative recommendations) and has been the subject of much philosophical debate. I will provide an overview of this debate and suggest ways we can think about facts and values that will enable this project to proceed. In

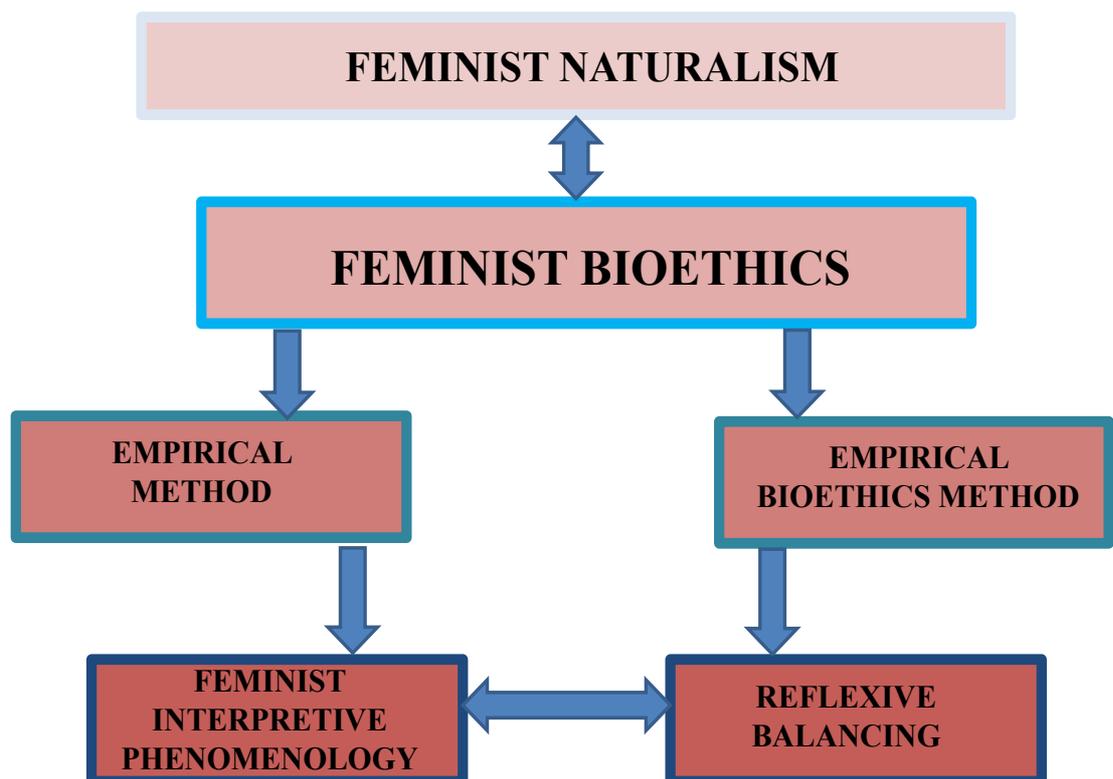
the final part of this chapter I will discuss three empirical bioethics methods that can be used to combine empirical data and ethical theory. I will argue that ‘reflexive balancing’ is particularly compatible with this feminist project because it employs a quasi-moral foundationalism which allows some beliefs to be treated as though they are epistemically privileged (Ives, 2014). This moveable foundation provides a starting point for ethical inquiry to take place but in the knowledge that the foundation can be altered and changed if faced with insurmountable evidence. This quasi-moral foundation enables my commitment to “core feminism” to undergird this project: the commitment to seek and “eradicate traces of sexism and other oppressions wherever they may be found” (Donchin and Purdy, 1999, p.3). This commitment to the exploration of women’s and oppressed individuals’ moral experiences is the starting point for this inquiry as I seek to explore critical care nurses’ ethical experiences, to uncover any oppressive practices and suggest ways to overcome them.

Figure 1 (p.23) provides a representation of how the underlying methodology (feminist bioethics), epistemology (feminist naturalism), empirical bioethics method (reflexive balancing) and social science empirical methodology (feminist interpretive phenomenology) relate to one another and may be a useful tool to refer to in this chapter and in chapter 4.

Throughout this thesis, I will use the words ‘ethics’ and ‘moral’ interchangeably to mean the study of what is good or right. I use the word ‘bioethics’ rather than ‘medical ethics’ or ‘nursing ethics’ because I want to speak more broadly about the interdisciplinary activities between the healthcare professions, philosophy,

law, theology and increasingly the social sciences (Borry et al., 2005). I will use the terms ‘feminist ethics’ and ‘feminist bioethics’ interchangeably but I am mindful that feminist ethics refers more generally to the movement in the 1970’s and early 1980’s (Jagger, 2001); whereas feminist bioethics is a term used more recently to refer to the late twentieth century when second wave feminists turned their attention to the field of bioethics (Donchin and Scully, 2015).

Figure 1: Diagram of Methodology and Methods



2.2 Feminist Bioethics

Within this section I will provide a brief overview of the development of feminist ethical theory, feminist criticisms of ‘traditional’ or ‘mainstream’ Western moral philosophy (Rehmann-Stutter, 2010; Jaggar, 1991), and the ways in which this project is suited to a feminist bioethics approach.

Gotlib (2015) describes the rise of feminist ethics as a movement against traditional moral philosophy in which the moral agent is viewed as an autonomous actor, rationally deliberating from universal, abstract principles about the ‘right’ thing to do and “unburdened by the non-ideal constraints of luck (moral and otherwise), circumstance and capability.” Indeed, Jaggar (2001) suggests that Western moral philosophy and in particular the European Enlightenment tradition has let women down in five fundamental ways: by showing less concern for women’s interests than men’s; by trivialising ethical issues that occur in private realms such as the home, and therefore making it difficult to raise questions regarding “the justice of the domestic division of labour” (p.530); by suggesting that women are not capable of the same level of moral reasoning as men; by overvaluing culturally “masculine” traits such as autonomy, independence and domination and underrating “feminine” qualities such as emotion, interdependence and community; and by favouring masculine ways of moral reasoning such as universalisation, rules and rights over female ways of moral reasoning which emphasise relationships, responsibilities and particularity. Typically, many traditional approaches to moral philosophy focus on abstraction, reason and logic as the route to moral knowledge, examples of which can be found in the work of Kant, Spinoza and as Walker (2009) argues,

Sidgwick. These philosophers minimize the social, political, physical and power differentials that, feminists argue, are pivotal within everyday life and impact not only on which ethical concerns are deemed to be important but also how moral deliberation plays out. The feminist critique suggests that the abstraction and neutrality of much moral philosophy thus far has communicated a male ethics which suggests that “the ‘view from nowhere’ really did just turn out to be the view from the men’s room” (Brennan, 1999, p.861).

With these criticisms in mind, feminist theorists have developed several alternative approaches to traditional moral philosophy. One of which can be found in the work of psychologist Gilligan who separated male or masculine values and female or feminine values (Jaggar, 2001). Gilligan explored the moral development of women and concluded that they sought to resolve moral problems in a different way to men, suggesting that women were more concerned with honouring relationships than with fulfilling ethical principles such as fairness. Gilligan’s work has however been subject to criticism. Critics argue it is problematic to divide values into ‘men’s’ and ‘women’s’, and to generalise about ‘all’ or ‘most’ moral experiences, when they vary so widely within and across cultures (Jaggar, 2001).¹ Jaggar (2001) famously stated that “*feminine* is not necessarily *feminist*” (p.532) because more is required from a feminist response than simply drawing divides between genders. Brennan (1999) suggests that another approach could be to develop other gender-neutral

¹ To note, I explore the related tension between individual experiences and the need to form generalisations to develop themes in qualitative research in chapter 4.

approaches, as can be found in Slote's care ethics work. Sander-Staudt (2011) highlights how some care ethicists such as Slote have developed gender-neutral care theories that focus on care and empathy as gender-neutral virtues that provide the basis for morality. However, Sander-Staudt (2011) suggests that these approaches risk neglecting issues of equality and Brennan (1999) argues that it is not clear how this approach overcomes the criticisms of traditional moral philosophy as the focus is again upon abstract, universal qualities that we all share rather than upon particularities. A third option, which Brennan (1999) suggests most feminist philosophers have adopted, is to develop an ethics that is concerned with the unique lived experiences of women and those who are marginalised within society. However, feminist bioethics is not only concerned with topics that are of concern to women (Scully, 2010). As Jaggar (2001) points out, men and women's lives are so deeply intertwined that there is no clear divide, rather what feminist ethics seeks to do is bring a fresh perspective to ethical issues. What makes this project inherently feminist is not the fact that the nursing profession is largely female but an underlying commitment to issues of "voice, power, relationships" (Mullen, 2003, p.159) and particularity (Donchin and Purdy, 1999).

At this point, I want to provide a brief explanation and justification for why I have adopted a feminist bioethics approach rather than a care ethics approach. Although feminist ethics and care ethics share many similarities and many nurses work from a care ethics approach, I would place this project within the first category. This is for three reasons. Firstly, because I draw more upon the work of philosophers who I (and I suggest they) would regard as working in

feminist bioethics rather than in care ethics. Secondly, I find myself in agreement with philosophers Lindemann (1992), Nelson (Boyer and Nelson, 1992) and Kuhse (1997) who argue that an ethics of care is dangerously narrow in scope. Although caring is an important value, indeed an “indispensable element of good patient care” (Kuhse, 1997, p.152), it should not be regarded as ‘the fundamental value’ of nursing ethics (Boyer and Nelson, 1992 on Fry). Kuhse (1997) argues that it is not enough to simply state that one must be caring, we need to know what to care about and without these qualifications, “the concept of ‘care’ remains empty and fails to distinguish between the ‘goodness’ of say, a torturer and that of a human-rights activist.” (p.153). Therefore, whilst caring may be considered a necessary condition for an adequate ethics, it is not in itself sufficient (Kuhse, 1997).

Finally, I find myself convinced by arguments suggesting that care ethics risks perpetuating a slave morality. Some care ethics accounts fail to acknowledge the fact that women must also care for themselves and this risks the further subjugation of women (Boyer and Nelson, 1992). Indeed, Kuhse (1997) suggests that care ethics perpetuates the notion of the virtuous nurse who gives oneself entirely to one’s patients. Commenting on Nodding’s notion of caring as ‘engrossment’ Kuhse (1997) suggests that there is “a great danger in requiring that every nurse –patient encounter be a ‘total encounter’ and in thus setting the ideal of caring in nursing too high” (p.149) She questions whether this is even something that all patients would want: “It seems highly unlikely that every patient who enters hospital with a particular medical problem – say, to have her appendix or her varicose veins removed – would *want* the many

different nurses who look after her during her hospitalisation to make serious efforts to “enter her life space” (p.149). The expectation of nurses to form an intimate connection with all their patients in such a way seems to ask too much not only of the nurse but of the patient. Furthermore, it is also not entirely clear how a relationship of this kind would necessarily ensure ethical care; Lindemann (1992) argues to care is not enough. We also need to be able to uphold standards of justice (Card, 1990; Lindemann, 1992).

Paley (2002) suggests care ethics is more sinister still and suggests its dominance in nursing has in fact caused nurses to “collude with the ‘dominant discourses’ of power” (p.26). Paley (2002) argues that the care ethics movement mirrors the uprising of the slaves against the nobles that can be found in Nietzsche’s ‘Genealogy’. Paley draws an analogy between nurse theorists and care ethicists (slaves) who try to up-rise against medics and the ‘traditional medical model’ (nobles) on the basis that their approach is “morally bankrupt” (Paley, 2002, p.30). In a bid to gain power, the slaves (nurse theorists/care ethicists) rebel against the nobles (medics/medical model) and try to replace the nurse-doctor relationship with the nurse-patient relationship. This new world view, in which nurses are intimately and deeply connected to their patients, Paley (2002) labels the ‘caring paradigm’. However, despite the rebellion, “the political balance remains unchanged, but in fantasy” (p.30). Rather than provide a vehicle for change, care ethics in fact maintains the status quo. Paley (2002) is not alone in believing that a care ethic is unable to fully address nurses’ powerlessness within hierarchical power structures because of its emphasis on the caring relationship between nurse and patient (Boyer and Nelson, 1992;

Bowden, 2000). Kuhse (1997) also suggests that the care ethicist would struggle to meaningfully debate issues of justice and equity and the ‘division of moral labour’ that has fallen disproportionately upon women and minorities. There is of course common ground that can be sought between care ethics and feminist ethics (Bowden, 2000) but this is not the aim of this thesis. Instead, my aim is to provide a justification regarding why I have chosen a feminist bioethics approach.

Scully (2010) suggests four “methodological biases” that make a project suitable to a feminist bioethics approach, which I will discuss in the next few pages (p.132). These methodological biases, according to Scully (2010) show a commitment within feminist bioethics about “how to conduct research, how to frame arguments, or how to decide between competing claims that lie behind the choice of method.” (p.131).

(i) Focus on experience

Scully (2010) states that feminism is rooted in the simple observation that women’s experiences differ to those of men and that by focusing on experience, these differences can be reflected upon philosophically, sociologically and politically. Indeed, feminist philosophers working in bioethics have used, and advocated for, the use of narrative to explore moral experiences, notably Urban-Walker and Lindemann. As Gotlib (2015) states, narrative accounts commit to taking seriously “the multitudes of individual lives, and thus the multitudes of voices and interpretations of moral situations. What matters... is not so much a reduction of moral positions to a commonly-held single perspective, but an

opening up of a space for reasons and dialogues with equally morally worthy others, thereby expanding the possibility of a shared, rather than a unitary and monolithic, moral universe”.

Scully (2010) discusses how many feminist ethicists have used narrative and phenomenology to collect empirical data and ground their theory in lived experience. It is the integration of empirical data, or narrative, with feminist thought that makes this project not only a feminist bioethics project but a feminist empirical bioethics project (Scully, 2017). Both the “relational turn” in feminist bioethics and the concurrent “empirical turn” in “mainstream” bioethics have sought to contextualise moral problems and ground them in real-life experiences (Rehmann-Stutter, 2010, p.41; Borry et al., 2005, p.50). By exploring the lived experiences of UK nurses who have encountered ethical issues in their clinical work, their narrative can be revealed, treated as a valuable epistemic resource and their contribution added to the moral debate regarding moral distress and ethics in healthcare. As Mullen (2003) suggests, doing so “proves an effective tool to inform or subvert a mainstream armchair discourse” (p.158). I use the methodology of feminist interpretive phenomenology to collect the empirical data, and I will discuss the relationship between phenomenology and feminism in chapter 4. What I wish to focus on now is that a feminist bioethics approach takes individual experiences to be epistemically valuable and directs researchers to explore differences between individuals lived experiences, whilst phenomenology provides the methodological tools with which to collect and analyse this data.

(ii) Consciously linking the personal/private with the public/political

The second methodological bias is an examination of the divisions between personal and private, public and political spheres (Scully, 2010). Jaggar (2001) criticises Western moral philosophy for failing to attend to the moral dimensions of “so called private life” and issues such as sexuality and child rearing (p.532). Historically, nursing has been viewed as an essentially feminine task that is associated with the domestic sphere (Gamarnikow, 1978). This association and related problematic relationships within healthcare institutions seem to have perpetuated the notion that nursing is subordinate to medicine. Gamarnikow (1978) describes how the doctor-nurse relationship came to mirror the husband-wife dyad with the nurse subsidiary to the doctor, and the patient as the child (Gamarnikow, 1978). With the divisions drawn such, the “healing process was dependent not only on obedience *per se* but also, more importantly, on the harmonious relations between the two health care occupations” (Gamarnikow, 1978, p.109). Therefore, in order to do their jobs well, nurses were led to believe they had to obediently follow doctors’ orders (Gamarnikow, 1978). I have argued elsewhere that although the nursing profession have progressed, there is a long journey ahead: nursing work continues to be diminished in the media and political spheres, nurses are still not being adequately remunerated for their work and they continue to struggle to control their environment (Morley and Jackson, 2017). Adopting a feminist bioethics approach requires these spheres to be not only examined, but questioned and subverted (Jaggar, 2001; Scully, 2010).

Examination of these divides is also important for this project because of the inter-play between nurses' personal and professional ethical beliefs and how these may impact their experiences of moral distress and how we conceptualise it. These personal experiences also take place within a healthcare system that is publicly and politically owned. Feminist ethicists focus their attention to the way in which non-ideal agents navigate moral decision-making in non-ideal environments in order to incorporate their experiences into normative discussion (Gotlib, 2015). Nurses live their moral lives within non-ideal environments in which they are responsible for the care of patients and families, and yet often lack decision-making authority and struggle to be heard (Peter et al. 2014; Molloy et al. 2014; Reed and Rishel, 2015). Nurses are a socially and politically marginalised group within a healthcare system that, perhaps erroneously, strives for multi-disciplinary working. I suggest this is perhaps 'erroneous', because as Ilhaam and Gaskin (2010) highlight, multi-disciplinary working means that whilst individuals from different healthcare professions may come together, ultimate decision-making authority remains firmly with one discipline, or one person within the team. Within the NHS, this authority still remains with the consultant under whom the care of the patient is placed and challenging this requires an act of courage or strength (Hamric et al., 2015a). Whilst there may be good reasons for this to be so, such as for accountability purposes, it also means that no matter how vocal the nursing team is, the team members may never assume the role of an equal partner with their medical colleagues in a hierarchical power structure. Ilhaam and Gaskin (2010) suggest that instead we ought to be striving for a transdisciplinary approach where team

members are considered equal and work jointly to make decisions so that there is the “greatest potential to transform the tendencies of structured power relationships” (p.192). Nonetheless, it is within a multi-disciplinary environment that nurses find their moral choices and actions are constrained and diminished, and this has important ethical implications. A feminist bioethics methodology enables exploration of nurses’ moral experiences with a particular focus on the power structures and often conflicting dyads (doctor/nurse, nurse/patient, personal/private, public/political) that may affect moral distress experiences.

(iii) Attending to relationships of social, political and epistemic power

Rather than simply *frame* bioethical issues, Shildrick (2008) and Rehmann-Sutter (2010) discuss how feminist bioethics successfully *disturbed* “mainstream” bioethics (p.29; p.25). Rehmann-Sutter (2010) uses the first and second editions of the Encyclopedia of Bioethics (Fletcher, 1978; Milunsky, 1978; Evans et al., 1995) as an example. He highlights how in the first and second editions there was a failure of bioethicists to understand the impact of women’s experiences of prenatal diagnosis (PND) on the ethical implications of the procedure. In the first two editions, the authors discuss the experiences of the ‘parents’ and the ‘couple’ and frame PND as a provider issue rather than a decision that deeply impacts each woman and her unique experience of pregnancy (Rehamann-Stutter, 2010). Whereas by the third edition, not only were the authors of the entry women but the experiences of women who had undergone PND and subsequent termination of pregnancy were incorporated

into the ethical analysis. Rehmann-Stutter (2010) argues that this is an example of how feminist thought can change moral perceptions and contextualise thinking, providing a “relational turn” that illuminates different understandings and interpretations of ethical issues (p.41). Rather than analyse ethical issues out of context and in an abstract way, feminists seek to contextualise ethical issues with real life experiences so that they can attend to social, political, environmental and epistemic factors.

Indeed, moral distress does not operate within a vacuum but within a complex, hierarchical healthcare system in which societal biases operate. Feminist bioethics extends beyond the traditional power dyads of doctor-patient and physician-philosopher, embracing a much broader approach (Scully, 2010). Ilhaam and Gaskin (2010) argue that a preoccupation with these traditional relationships can “reinforce patriarchal tendencies in philosophy and medicine by privileging the perspectives of M.D.s [medical doctors] over nurses and female health care workers” (p.191). Using a feminist bioethics approach therefore allows exploration of the social hierarchy and power relations that permeate nurses’ daily working lives. In chapter 3, I will discuss the moral distress literature that is already saturated with narratives of powerlessness, the difficulties of navigating challenging power-dynamics and the privileging of ‘medical’ knowledge over ‘nursing’ knowledge (Peter et al. 2014; Molloy et al. 2015; Reed and Rishel, 2015).

Holmes (1999) also highlights how nurses face the threat of bioethics being dominated by doctors who can uphold the “cognitive authority” of medicine

(p.47). Ilhaam and Gaksin (2010) state that this “cognitive authority renders the truth claims of medicine as valid, while its concurrent social authority demonstrates the pervasiveness of the medical model in social institutions.”

(p.193) Medicine has tended to dominate the clinical and ethical environment of institutions because medical expertise is privileged within Western societies. However, over the last thirty years, the concept of moral distress has provided opportunities for nurses to have a voice within bioethics, serving as evidence of nurses’ ethical struggles within the clinical environment. Gallagher, for example, argues that one of the strengths of moral distress is that it draws attention to and highlights the challenges to ethical aspects of care practices (reported in Morley, 2016). Moral distress serves as a mechanism for nurses to highlight their oppression inside the clinic to the academy. However, whilst there has been a strong tradition of nursing in bioethics in the United States (US) (Grady, 2016), nurse ethicists in the US still struggle to draw attention to the everyday ethical concerns of clinical nurses within bioethics discourse (Ulrich, 2016). Given the lack of nurse ethicists in the UK, the struggle to incorporate nursing voices into bioethics is still at its infancy. A feminist methodology, with a commitment to representing disempowered and marginalised groups, provides the tools required to help bring nurses’ ethical concerns to the fore. It must also be noted that whilst I acknowledge that moral distress is likely to be experienced by all healthcare professionals and even beyond the realms of healthcare, the purpose of this particular study is to explore nurses’ experiences of moral distress, and so this study will be firmly focused on nurses’ experiences.

(iv) A commitment to social and political change

Finally, the distinctly normative nature of feminist bioethics makes it a suitable methodology for this project. The aim of this project - to understand nurses' lived moral experiences in order to inform the concept of moral distress and to develop responses to it - mirrors that of many feminist bioethics endeavours - to understand women's and oppressed individuals moral experiences with the aim of providing a route to end oppression (Brennan, 1999; Jaggar, 2001). Indeed, feminist bioethics shares this normativity with the feminist political movement which was made famous through women's suffrage.

This methodological bias is intimately connected to the third because once social, political or epistemic inequality has been recognised, feminist bioethics commits to initiating steps for change. Warren argues that discussion surrounding constraints on moral agency must also be "supplemented by an ethics of empowerment" (Donchin, 2010, p.17). Indeed, feminism originated as a movement dedicated to social and political change and consequently feminist bioethics requires both academic rigor and socio-political commitment (Scully, 2010). By adopting a feminist empirical bioethics methodology, I can both examine the moral experiences of nurses and commit to providing routes for change and empowerment, rather than perpetuating a narrative of moral suffering and powerlessness that has been a criticism of some nursing literature (Paley, 2004). Indeed, Scully (2010) states that there is a "transformative imperative undergirding" feminist bioethics (p.132). I am committed to working towards placing the experiences and ethical lives of nurses on the political

agenda (Morley and Jackson, 2017).

To conclude, a feminist empirical bioethics approach can be used to explore a range of different topics so long as these four commitments are integrated into the research method. Referencing Code, Scully (2010) stresses how a feminist approach must always retain its “critical stance” (p.133) and not give in to the “tyranny” of experience (Code, 2002, p.164). Later, I will discuss ways in which feminist empirical bioethics can integrate experience/empirical data (‘facts’) with ethical theory (‘values’) and still retain its ‘normative mandate’ (Goldenberg, 2005; Widdershoven and van der Scheer, 2008a). However, before doing this I will first introduce the epistemology that underpins this project.

2.3 Feminist Naturalism

Before moving on to discuss some of the empirical bioethics methods that have been developed in recent years, I will first describe the underpinning moral epistemology of this project. There are different moral epistemologies that are used by, and seem consistent with feminist bioethics. One of the most dominant, and the one used within this project is ethical naturalism, or as Walker (2009) coins it ‘Feminist Naturalism’. Jaggar (2000) highlights how “naturalism” has many inconsistent meanings in Western philosophy but I will use the term similarly to Jaggar (2000), to encompass a denial of a “pure realm of reason, to be studied by methods that are distinctively philosophical” and “Instead, it [naturalism] advocates multidisciplinary approaches to understanding human

knowledge, utilizing the findings and methods of a range of disciplines with special reliance on the empirical sciences” (p.457). Throughout history, many traditional Western moral epistemologies have emphasised the importance of rationality as “the essential human characteristic” to which objective moral truths may be accessed (Jaggar, 2000, p.454). One of the most obvious examples is the work of Kant. Kant built his moral philosophy upon the importance of abstraction, universalisation and practical reason with his Categorical Imperative which states, “act only in accordance with that maxim through which you can at the same time will that it become a universal law” (Korsgaard, 1997, p.18). Kant stressed the importance of the Categorical Imperative as an expression of human reason, arguing that so long as we act according to this imperative, we act rationally, and therefore morally. Jaggar (2000) highlights how this emphasis on rationality, along with arguments that women lack reason, ensured that women were viewed as less morally valuable than men. Many feminist philosophers however deny the importance of rationality and abstract reasoning in moral epistemology, instead adopting feminist naturalism. Feminist naturalism rejects the abstract, universal principles, and timeless moral reasoning as espoused by philosophers such as Kant; it rejects a realm of truth-apart moral facts or properties, and instead positions morality within the “practice of particular people in particular times, places, cultures, and professional environments” (Walker, 2009, p.5). Decision-making is seen to be dependent upon context and interpersonal relations, rather than as an exercise of pure reason, and at its core is a practice in which “moral justification is a function of what we *do* with what we think we know” (Verkerk and Lindemann, 2012 p.11).

Naturalising ethics requires an acceptance of ethics as set within the empirical world, not discoverable a priori but instead a-posteriori. It is a form of moral realism that tries to avoid the conclusion that moral judgements “track truths” in a world that is independent to ours (such as Plato’s world of ‘The Forms’) but instead “are part of the naturally given expressive and adaptive equipment of human beings” (Walker, 2009, p.2). Lenman (2006) describes moral realism as an “attractive view” because it tries to make sense of morality as capable of truth and falsity but rather than committing to a realm of moral knowledge, naturalists stipulate instead that moral value is part of the natural world. Because feminist naturalism grounds morality within the social, empirically-discoverable world, as part of particular historical and cultural locations, it is particularly compatible with the ‘empirical turn’ within bioethics (Walker, 2009). Gathering empirical data from stakeholders is viewed as a legitimate activity that can inform and enable normative reasoning. In fact, Walker (2009) argues that a bioethics which fails to be “socially critical and power-sensitive” is “neither epistemically sound nor fully accountable” (p.12-13). The moral epistemology of feminist naturalism is therefore coherent within an empirical bioethics approach as it demands that “in ethical theorizing we look at *society* in addition to science and at the dominance of some voices and the exclusion of others within societal and professional conversations about morality and ethics” (Walker, 2009 p.3). Other approaches and theories in philosophical ethics tend “to absorb or obscure the biases, hierarchical relations, and exclusive, oppressive, or violent social arrangements that many human societies sustain and even celebrate” (Walker, 2009 p.3). Previous research on moral distress suggests that understanding these contextual issues and their impact on moral

distress may prove important to our conceptualisation of it. Due to limitations and constraints within this thesis, I am unable to defend this position but instead make clear the epistemological commitments of this position and how it coheres with the overall project.² To simply state rather than robustly defend my metaethical position is an agreed upon practice within empirical bioethics. This is largely because a defence of such epistemological and ontological issues which have been debated for centuries would constitute a thesis in itself. Indeed, in a European consensus paper using a modified Delphi method, Ives et al. (2018) highlight how there is diversity amongst empirical bioethics researchers regarding the metaethical and epistemological commitments that underpin their methodological positions. Due to this diversity, this particular group of

² There are a number of different philosophers in metaethics who have developed theories regarding what we mean when we talk about ethics and morality and it is unlikely we will ever resolve this debate. Feminist naturalism was selected because it provides the best fit for this project. For example, cognitivists argue that moral judgements express beliefs which are capable of being true or false. G.E. Moore was a prominent cognitivist and non-naturalist because he argued that although moral properties exist, they cannot be reduced to ‘natural’ properties and those who reduce them to natural properties are committing the naturalistic fallacy. Moore’s position will be explained more fully in the next section as the naturalistic fallacy is commonly taken to pose a threat to empirical bioethics. Non-cognitivists argue that moral judgements are not capable of being true or false. For example, Simon Blackburn was a quasi-realist who argued that moral judgements express sentiments, and A.J. Ayer was an emotivist who famously developed the ‘boo-hurrah’ theory as he claimed moral judgements simply expressed approval/disapproval.

empirical bioethics experts agreed researchers should “‘make clear and explicit’ rather than ‘justify or defend’ because it was felt, overall, that it would be unreasonably burdensome to expect researchers to defend all meta-ethical and epistemological commitments and assumptions” (Ives et al., 2018, p.13). It was also agreed that there should be no agreed prescriptive standard regarding how an empirical bioethics researcher integrates the empirical and normative parts of their project but rather that it must be done transparently, and it must be justified (Ives et al., 2018). In the next section, I will discuss three possible empirical bioethics methods and justify why I have chosen the empirical bioethics method of reflexive balancing to integrate the empirical and normative work.

2.4 Empirical Bioethics

2.4.1 Introduction

In the previous section, I discussed the ‘methodological biases’ or minimal requirements for a feminist bioethics project. The first of these is exploration of women’s and marginalised individuals’ moral experiences. As I have highlighted, the combination of feminist theory with narrative (first-hand accounts, literary accounts) is an accepted practice in feminist bioethics. Within this project, I am combining feminist theory with nurses’ first-hand accounts of their experiences of moral distress to form a feminist empirical bioethics project.

In this section, I will introduce empirical bioethics, common criticisms of

empirical bioethics and two philosophical debates that raise challenges for empirical bioethics: the fact/value distinction and the naturalistic fallacy. It is beyond the scope of this thesis to provide an in-depth analysis of these challenges or to provide unequivocal solutions. I will instead highlight the issues they raise for empirical bioethics and propose ways these challenges can be reconciled so that I can proceed with this approach. I will discuss three empirical bioethics methods and conclude that ‘reflexive balancing’ offers the most suitable tools for this project.

2.4.2 The “Empirical Turn” in Bioethics

Borry et al. (2005) used the phrase ‘empirical turn’ to describe the integration of the social sciences and social science methods of data gathering into the interdisciplinary activities of bioethics. However, the term ‘Empirical Bioethics’ may refer to a range of different research activities. Ives et al. (2017) point out that the term could be used to describe empirical research of ethical issues in practice, empirical verification of moral arguments or empirical appraisal of the implementation of ethical arguments or interventions in practice. However, these might be considered “broader church” typologies (Ives et al., 2017, p.X). Following the recent European consensus paper, the types of empirical bioethics project that I am primarily concerned with involves “interdisciplinary activity in which empirical social scientific analysis is integrated with ethical analysis in order to draw normative conclusions” (Ives et al., 2018, p.2). The authors emphasise that this view of empirical bioethics may not be accepted by all and they haven’t reached total consensus (being only a small group of European experts working in empirical bioethics) but are

working *towards* one. Nonetheless, for Ives et al. (2018), the mark of an empirical bioethics project is interrogation and integration of the empirical with the normative. The aim is not to simply accept the empirical data as providing justification for the normative recommendations but to integrate the two. I adopt the same focus of empirical bioethics as Ives et al. (2018) because this position aligns with feminist bioethics which similarly seeks to strike a balance between uncovering experience without giving into the “tyranny” of experience (Code, 2002, p.164), and combining experience and normativity (Brennan, 1999; Jaggar, 2001; Gotlib, 2015). This project seeks to be normative in two ways: to provide normative conclusions about how we ought to understand the concept of moral distress in a UK setting, and secondly, to provide normative recommendations about how we ought to respond to moral distress. Both normative issues are accepted within Ives et al.’s. (2018) characterisation of an empirical bioethics project.

2.4.3 Common Criticisms of Empirical Bioethics

Similarly to feminist critiques of abstract philosophical theorising and the ‘relational turn’ that grew amongst feminist theorists (Rehmann-Sutter, 2010), the ‘empirical turn’ grew from the notion that grounding ethical analysis in empirical data could produce better ethical theories, and normative conclusions could be reached based upon real-life ethical issues (Widdershoven, 2007). Hedgecoe (2004), a social scientist, highlights how philosophical bioethics has prioritised idealised, rational thought, to the detriment of social and cultural factors. Hedgecoe (2004) cites the examples of Utilitarianism and Principlism and how these pre-made ethical theories have been applied to ethical problems.

Hedegcoe (2004) finds this deeply problematic and states, “what counts as an ethical problem in the first place, prior to the application of ethical theory, is socially constructed.” (p.126) Many ethical theories are insufficient because they fail to factor in the social aspect - the ‘is’ of lived experience - into the ‘ought’ of normative judgement. As a result, Hedegcoe argues, “This gap isolates bioethics from practice, undermines the validity of its claims, and reduces its contribution to policy debates surrounding bioethics topics.” (p.121).

Despite the appeal of grounding one’s ethical analysis and normative conclusions in real-life experience, the development of empirical bioethics has been subject to criticism from both social science and philosophical perspectives. Ives et al. (2018) state, “much ink has been spilled in recent years either extolling or critiquing the rise of the ‘empirical turn’ in bioethics” (p.2). Social scientists (such as, Hedegcoe (2004) and Haimes (2002)) have criticised ‘bioethics’ for failing to fully incorporate social science methodologies into their empirical bioethics methods, assigning them the role of ‘handmaiden’ or fact gatherer, and they worry that empirical bioethics researchers are not engaging with the insights that the social sciences can provide. Whereas Strong et al. (2010) raise philosophical concerns and argue that empirical bioethics risks over-emphasising data which diminishes philosophical analysis and obscures normative arguments. Strong et al. (2010) also suggest that empirical bioethics disregards the ‘is-ought gap’, commits the naturalistic fallacy, and/or violates the fact-value distinction. These last three philosophical criticisms will be dealt with in the next section as they are more complex and are commonly found within the literature as reasons to dismiss empirical bioethics. I will first

however provide responses to the social science concerns raised here.

Firstly, empirical bioethics researchers must engage with their chosen social science method so they are able to explain and justify how the method coheres with their overall project (Singh, 2017; Ives et al., 2018). It is not enough to use for example, ethnography without engaging with the epistemological commitments of that method. Secondly, researchers must ensure the epistemological commitments of the project enable theory and practice to interact. The underlying epistemology of this project (feminist naturalism) lends itself particularly well to an empirical bioethics approach because morality is seen as largely socially constructed. In feminist naturalism, ethical theory and the social world are viewed as deeply interwoven; the way we identify, respond to, and justify moral problems is heavily dependent upon context, relationships and responsibilities. A feminist approach can eliminate worries that the bioethical approach prioritises idealised, rational thought at the expense of social and cultural factors (Hedgecoe, 2004).

In response to philosophical concerns that an empirical bioethics approach risks over-emphasising empirical data and losing its normativity, Hedgecoe (2004) provides useful insights as he argues the empirical bioethics researcher needs to leave space for the philosopher. The aim of empirical bioethics is to incorporate the best aspects of both disciplines and empirical bioethics without philosophy would lack 'bite' and 'rigour', and risk becoming a mere commentary of unethical systems and practices, rather than a challenge (Hedgecoe, 2004). It is important that an empirical bioethics approach both takes seriously the social

sciences methodologies whilst maintaining a critical philosophical stance so that empirical bioethics retains its ‘normative mandate’ (Goldenberg, 2005).

Indeed, Hedgecoe (2004) advocates for a ‘critical bioethics’, a bioethics that interrogates and questions the claims of other bioethicists, clinicians and scientists. Again, this mirrors feminist approaches as Scully (2010) stresses that a feminist bioethics approach must always retain its “critical stance” (p.133). This means the empirical bioethics researcher must not unquestioningly and unreflectively adopt the empirical findings but question and challenge them (Ives and Draper, 2009). Ultimately, as Ives (2014) argues, bioethics has always been interdisciplinary and empirical bioethics may be best interpreted as engaging with this and attempting to address the inevitable methodological challenges. Before I discuss some recent empirical bioethics methods, I will address three common philosophical challenges directed at empirical bioethics. I will outline the key challenges that these philosophical arguments pose for an empirical bioethics method and suggest ways we can think about facts and values that will enable this project to proceed.

2.4.4 The Fact/Value Distinction and the Naturalistic Fallacy

Critics argue there is an irresolvable tension at the core of empirical bioethics which stems from attempts to marry empirical data or ‘facts’ with ethical theory, which deals with norms and ‘values’: the fact/value distinction (Widdershoven and van der Scheer, 2008a). Supporters of the fact/value distinction claim facts and values have fundamentally different properties and, in the case of empirical bioethics because of this, facts cannot tell us anything about values.

The fact/value distinction is attributed to David Hume, but became part of the larger philosophical movement of Logical Empiricism. Hume divided knowledge into 'relations of ideas', discoverable a-priori and through 'mere operations of thought' which consist of mathematics and logically true statements, and 'matters of fact' which depend upon the way the world is and are derived from sense-experience; for example, I know that the sun is shining because I can see and feel it (Gardner, 2006). Matters of fact, which are empirical and scientifically observable, can therefore be verified or falsified, whereas values are something else entirely, for example preferences or desires. Such a distinction is troubling for an empirical bioethics approach because Hume can be interpreted as saying "when an 'is' judgement describes a 'matter of fact', then no 'ought' statement can be derived from it" (Putnam, 2002, p.15). This putatively undermines the aim of empirical bioethics in which empirical data is gathered and used as the basis of normative discussion. I will put aside my contention that empirical data or 'facts' - as they are taken to be for the purposes of this critique - are actually theory laden (Frith, 2012) and reliant upon interpretation, in order to engage with this challenge (Carter, 2009; Frith, 2012).

Putnam (2002) argues that it is the interpretation of Hume's *distinction* as a *dichotomy* that has created problems. Putnam makes comparisons with another significant distinction within this movement: the analytic/ synthetic distinction. Kant claimed that analytic truths are true in virtue of meaning alone, the famous example being 'all bachelors are unmarried men'. Whilst synthetic truths,

similarly to ‘matters of fact’, are true because of the way the world is, for example conventions are socially constructed. Putnam (2002) highlights how both of these distinctions were taken by the logical positivist movement and interpreted as dichotomies. Lines were drawn between statements of fact, which were said to be “scientifically significant”, whilst anything not factual (often relating to the ethical, metaphysical and aesthetic) was deemed to be “cognitively meaningless” (Putnam, 2002, p.10; p.29). Putnam (2002) compares these distinctions because he thinks their development into dichotomies is analogous: both distinctions were inflated and used to undermine the creation of knowledge that wasn’t built on facts (Gardner, 2006).

Interpreted as a dichotomy, Hume’s argument implies a significant point about the epistemology of value; for Hume, all knowledge is built upon sense-experience and since values cannot be grounded empirically, they have very little worth for knowledge building. This is a type of non-cognitivism that espouses the belief that values are not truth-apt and therefore can be reduced to mere sentiment (McMillan, 2017). This interpretation undermines this project since exploration of nurses’ experiences would only shed light on how the world ‘is’ and any inferences about values would not only be illogical but would fail to be truth-apt and reducible to sentiment, or intuition. The question therefore is how we can resolve this dichotomy in order to justify an empirical bioethics approach?

Putnam’s (2002) argument is that it is not a dichotomy, but instead a mere thesis:

“If we deflate the fact/value dichotomy, what we get is this: there is a distinction to be drawn (one that is useful in some contexts) between ethical judgements and other sorts of judgements. This is undoubtedly the case, just as it is undoubtedly the case that there is a distinction to be drawn (and one that is useful in some contexts) between *chemical* judgements and judgements that do not belong to the field of chemistry. *But nothing metaphysical follows from the existence of a fact/value distinction in this (modest) sense.*” (p.19)

Putnam argues that once we stop equating ‘values’ with ‘ethics’ it becomes clear that science presupposes values of a different kind: epistemic values. He argues that when we choose a theory about the world, it is chosen on the basis of a value, for example we accept or reject certain theories based on judgements about coherence and simplicity. Putnam (2002) highlights how these are epistemic values, and because we make sense of the world by applying these epistemic values, this is illustrative of the deep entanglement between facts and values and is evidence against the existence of a dichotomy. Furthermore, Putnam (2002) highlights how the very language of the logical positivists exemplifies this entanglement because they described facts as “cognitively meaningful” and values as “nonsense” thus using terminology that, on their interpretation, are not observable but are theoretical and therefore meaningless (p.34).

Putnam (2002) therefore gives us good reason to doubt the existence of a distinct dichotomy between facts and values, arguing instead that they are

deeply entangled. If we understand facts and values to be entangled then it follows that facts can tell us something about values, but that there is work to be done in-between. Indeed, this is readily accepted by empirical bioethics researchers and as Ives and Draper (2009) state, “no sane defender of empirical bioethics is likely to suggest that we unreflectively use empirical data to determine what we morally ought to do” (p.254). The success of an empirical bioethics project rests upon a methodological approach that ensures considerate engagement with empirical data by providing an “internally coherent epistemology and theoretical framework” (Ives et al., 2017, p.8). Empirical bioethics researchers must therefore combine facts/values in a thoughtful way so that they are mindful of philosophical issues and can avoid incoherence (Ives et al., 2017).

Feminist naturalism is an appropriate epistemology as it is coherent with Putnam’s position. Feminist naturalism places morality within the social, empirically-discoverable world, dependent upon particular historical and cultural locations (Walker, 2009). The way that values are perceived and understood is therefore dependent upon the way the world is experienced. There is no clear divide between facts and values, as they are mutually informing and each are required to help us make sense of the world. Indeed Putnam and Walsh (2007), argue that, “the familiar arguments for relativism or non-cognitivism from the disagreements between cultures concerning values... could be modified to read that there are disagreements between cultures concerning what beliefs are more ‘coherent’, ‘plausible’, ‘simpler as accounts of the facts’, etc.... Thus, even when the first-order judgments in dispute are the paradigmatic cases

of the ‘factual’ in our time... the decision as to their warranted assertability involves value choices”. (p.183) For example, when a nurse chooses which patient to prioritise in triage, this is influenced by facts (which patient has injuries that more urgently require attention) but it also a value judgement (which patient ought to receive access to limited resources). The values that we choose to prioritise in a given situation are also influenced by relevant facts.

A second well-known philosophical challenge for empirical bioethics is the Naturalistic Fallacy which originates from G.E.Moore, a prominent cognitivist and non-naturalist. He argued that moral facts and properties are truth-apt and exist independently of human opinion and therefore they aren’t true in virtue of ‘natural’ properties and should not be defined as such (Miller, 2003). By ‘natural’, Miller (2003) suggests Moore meant the natural sciences and psychology, with ‘non-natural’ properties being those that are “neither causal nor detectable by the senses” (p.11).

Moore argued that John Stuart Mill, a famous proponent of Utilitarianism committed the naturalistic fallacy because he likened ‘happiness’ to ‘good’. However, because Moore takes ‘good’ to be non-natural, it couldn’t be reducible to other facts in the world and he tried to show this with his Open Question Argument (McMillan and Hope, 2008; Ives et al., 2017). Moore argued that to say “‘x is good’ is equivalent to ‘x is pleasure’” and if this were true, Moore argued, “the judgement ‘pleasure is good’ would be equivalent to ‘pleasure is pleasure’”, which Hurka (2015) highlights is an uninformative tautology that leaves the question regarding whether it is ‘good’ open. Moore

argued that this highlights how values cannot be understood purely in terms of natural properties. McMillan (2017) suggests that Moore is concerned by attempts to reduce claims about non-natural properties, such as statements about what is 'good' to matters of fact, and states that Moore seems "driven to protect the importance of viewing the good or the beautiful in their own terms...the irreducibility of non-natural properties preserves their status as things to which we should aspire." (p.22) Miller (2003) suggests Moore believed 'good' isn't definable at all, even in terms of non-natural properties.

Philippa Foot (2002) rejected this distinction between natural and non-natural properties, arguing that words such as 'good' are both descriptive and normative because we have real reasons to be good and not to be bad. Foot (2002) uses the example of a person interpreting behaviour as rude. Foot suggests that for one's behaviour to be considered rude, it needs to fulfil certain conditions. If the behaviour cannot fulfil these conditions then it should not be interpreted as rude. The non-natural property, or the value (rudeness), relies on the fact (or the natural property), in order to be justified, and therefore the concept 'rude' can be considered a 'thick ethical concept' that is able to operate on a descriptive and normative level, and is deeply entangled with the fact. As Parker (2009) suggests:

"This is an appealing picture for the naturalistically inclined, with moral evaluation and action needing neither a special explanation from a noumenal sphere of mysterious non-natural properties, nor relegation to a non-rational emotivist realm" (p.205)

As with Putnam, Foot cannot provide an absolute reason to reject Moore's argument but again provides us with enough reason to see why an absolute distinction between natural and non-natural properties is not altogether clear. By breaking down the distinctions between facts and values, and natural and non-natural properties, and suggesting that they are interrelated in order for us to make sense of the world and the moral values we experience, we have enough space to proceed with an enquiry that combines both ethical theory and lived experience. However, I am mindful that there is still work that needs to be done to provide normative conclusions from empirical data and in the next section I will discuss three empirical bioethics methods which provide tools and coherent frameworks for combining facts and values.

2.5 Empirical Bioethics Methods

In this section, I will outline three consultative empirical bioethics methods and the approaches they suggest for reaching justified normative conclusions. A number of different methodologies have emerged in bioethics and in a recent systematic review of the literature, Davies et al. (2015) found 32 distinct methodologies that they identified as dialogical, consultative or a combination of both. Dialogical methods are centered around dialogue between the researcher and participants with the aim of reaching shared understanding and a resolution to a particular ethical problem (Davies et al., 2015). Whereas in Consultative methods the researcher is an "external 'thinker'" who, analyses and reaches normative recommendations independently of the participants (Davies et al., 2015, p.7). I have chosen to focus on discussing different

consultative approaches here on the basis that this is the approach I have taken. I did not want to provide an account of moral distress based upon consensus from one group of UK participants but rather I wanted to balance these experiences with previous empirical and theoretical research to reach a coherent account of moral distress. Using this approach, I hope to increase the transferability of my account as it encompasses both lived experience of UK nurses and key pieces of theory and wider evidence.

2.5.1 Reflective Equilibrium

Reflective Equilibrium was made popular through the work of political philosopher John Rawls, and has come to be a common method within empirical bioethics and in bioethics more broadly (as a guide to decision-making in clinical contexts) (Arras, 2009). I will however limit my discussion to reflective equilibrium as an empirical bioethics method. reflective equilibrium uses a coherence account of justification that requires the researcher to work through beliefs or ‘intuitions’ in order to build a coherent set of beliefs (Daniels, 1979; Walker, 2009) . For Rawls:

“Moral statements are correct when they accord with reasonable moral principles, and moral principles are reasonable when they are the product of a reasoning procedure that incorporates all the relevant requirements of practical reason... [and] moral statements are sound or true, not in representing a prior order of moral facts but when they accord with principles that could or would be accepted by fully rational persons in an objective procedure of practical reasoning” (Freeman, 2006, p.27- 28).

Central tenets of reflective equilibrium are therefore method, practical reason and coherence. I have put together the following steps to try and articulate a method for reflective equilibrium:

1. In their interpretation of reflective equilibrium (named Normative Empirical Reflective Equilibrium), van Thiel and van Delden (2017) propose four sets of beliefs that must first be identified – although with the caveat that the best combination of elements is dependent upon the purpose for which reflective equilibrium is being used.
 - (a) Considered moral judgements or moral intuitions
 - (b) Morally relevant facts
 - (c) Moral principles
 - (d) Background theories or ideals
2. According to Daniels (1979), these sets of beliefs must be filtered to include only those that the Thinker³ is relatively confident in.
3. These sets of beliefs are used as “provisional fixed points” that are scrutinised and examined from every possible angle (Arras, 2009).
4. The Thinker incorporates the moral intuitions of relevant agents into their set of beliefs, incorporating anything that may be relevant through a process of open inquiry (van Thiel and van Delden (2017) referencing Ives (2014)).
5. Empirical research is conducted to obtain empirical data on moral intuition or morally relevant facts (van Thiel and van Delden, 2017)

³ I am borrowing the term ‘Thinker’ from Van Thiel and Van Delden (2017) to mean the researcher that is conducting the empirical bioethics project.

6. With these in mind, the sets of beliefs are weighed up using philosophical argument to support/reject each set of beliefs until coherence is reached. According to Daniels (1979), the use of philosophical arguments to reach coherence makes this ‘Wide Reflective Equilibrium’.
7. The researcher must move back and forth between these four sets of beliefs until they arrive at equilibrium such that the background theories show that the moral principles are more acceptable than the alternatives on grounds that are independent to the considered moral judgements (Daniels, 1979).
8. Based on his interpretation of Daniels (1979), Arras (2009) suggests that background theories can provide independent justification for considered moral judgements.

I suggested the three central tenets of reflective equilibrium are method, practical reason and coherence. However, the issue that immediately struck me whilst trying to put these steps together was a distinct lack of clear guidance regarding how to conduct reflective equilibrium. Rawls did not originally construct reflective equilibrium as a method for justification to be used within empirical bioethics and therefore the steps are not altogether clear. Secondly, there are conflicting reports regarding how these steps should be followed. Of course, different perspectives regarding research methods are common-place but considering the complexity of empirical bioethics research, a clear set of steps the researcher can follow is important. The two empirical bioethics methods that I discuss in the next section both provide clear steps to follow.

The second central tenet for Rawls was practical reason. However, Frith (2012) critiques reflective equilibrium on the basis that Rawls idealised human rationality which is required for the weighing and balancing of beliefs, and argues that coherence is a vague concept. Indeed, feminist critique of reflective equilibrium have stemmed from similar observations, as Nussbaum (2006) (quoting Rawls (1999)) highlights, his suggestion that judgements “made with hesitation” or “given when we are upset or frightened” must be discounted and not added into the balance of beliefs can be read as Rawls discounting emotion-based judgements (p.490). Nussbaum (2006) suggests that such an elimination of emotion within reflective equilibrium is the result of “Kantian bias against emotion” (p.490) and discusses how emotions such as indignation and love play an important role in recognising injustice. Nussbaum (2006) argues that we need to determine which emotions are based on true judgements and those which are true and relevant to a conception of justice ought to be incorporated into our reflective equilibrium process.

Despite raising these criticisms, Nussbaum (2006) defends reflective equilibrium against these charges and argues that Rawls (1999) does provide a sufficient role for relevant emotions (such as indignation and resentment) into his conception of justice. Indeed, due to REs egalitarianism, wide reflective equilibrium is an accepted method amongst some feminist theorists, for example Walker (2009). Walker (2009) highlights how wide reflective equilibrium is compatible with a naturalistic moral epistemology because it is a

posteriori and so does not privilege moral principles and theories, allowing that they are revisable in light of recalcitrant experiences. As Arras (2009) states, reflective equilibrium “doesn’t play favorites with regard to the various *kinds* of beliefs, whether they are about cases, principles or background theories. No single stratum or cluster of moral considerations is privileged.” (p.184).

The third tenet is coherence. reflective equilibrium is a non-foundationalist theory that relies solely on justifying normative conclusions by their coherence within a set of beliefs, and the analytic process required to reach a conclusion is one that involves balancing judgements and principles with the perspectives of the participants in mind (Widdershoven, 2007). As Ives (2014) states, reflective equilibrium rejects top-down approaches and bottom-up foundationalism to ethical problem-solving and instead seeks ‘coherence’ between beliefs in order to attain epistemic justification. Arras (2009) suggests that one reason for the popularity of reflective equilibrium is its appeal to many different factions in the ‘method wars’ due to its flexibility, inclusivity and egalitarianism. These strengths all seem to stem however from REs coherence requirement, which is perceived as a weakness by some commentators.

Ives (2014) levels three criticisms at reflective equilibrium, all of which spring from its coherentism; firstly, reflective equilibrium is unable to account for ‘historical accident and prejudice’ (quoting Strong (2010)). For example, an individual may hold a set of prejudiced beliefs but because they are held as coherent within their set of beliefs, on reflective equilibrium they would be

‘justified’. Secondly, citing Arras (2009), there is the practical problem of indeterminacy- indeterminacy in knowing which beliefs need to be pruned, and knowing when coherence has been reached. Finally, Ives (2014) claims that reflective equilibrium is ‘over-egalitarian’ and Arras (2009) suggests reflective equilibrium is too comprehensive since each proposition must be subjected to the entire network of beliefs to know if it is morally justified. As a research method, it is overly-cumbersome since those performing reflective equilibrium must treat each belief as holding equal epistemic weight (Ives, 2014).

To conclude, despite the popularity of reflective equilibrium it does have significant weaknesses: the method is not altogether clear and there is doubt regarding how one can begin the process of justifying and forming a coherent belief set without some foundational beliefs. To proceed with a moral enquiry, it does seem that some beliefs might need to be ‘epistemically privileged’ over others to build a foundation upon which other beliefs can cohere (Ives, 2014).

2.5.2 Symbiotic Bioethics

Frith’s method of ‘Symbiotic Bioethics’ (SB) is based upon a naturalised moral epistemology that places value on both ethical practice and ethical theory. Frith (2012) argues that ethical theory should not be applied in a top-down approach because theory and practice are mutually informing:

“Any ethical theory faces the problem of generalisations running out when confronted with particular situations; moral rules are indeterminate. However, it is the formulation of the moral rules, and how they can be revised and

interpreted in the light of experience and situations, that is important for my account and where it differs from the ‘traditional’ models of bioethics based on foundationalism.” (Frith, 2012, p.200)

In SB, ethical theory can be used to analyse and explore the morality of practice whilst practice and ethical norms can inform and amend theory, thus Frith (2012) states “ethical theories arise out of the practical problems, context and dilemmas that face us in bioethics – practice can inform theory just as theory can inform practice - the two are symbiotically related” (p.201).

Frith (2012) sets out five inter-related steps that are required to carry out SB:

1. Seek the views and opinions of key stakeholders - collect the empirical data.
2. Specify theories and principles that may be relevant and explore how they are informed by the empirical findings.
3. Use relevant ethical theory and principles as tools for analysis of the empirical data.
4. The theory used to analyse the data is built upon by the empirical findings.
5. The ethical theory and empirical data can be used to inform normative judgements.

Because Frith employs a naturalised moral epistemology which incorporates ethical theory in such a way that it is not deemed to be top-down and action-guiding but rather socially informed and constructed, SB is compatible with the underlying epistemology and feminist bioethics methodology of this project. However, Frith (2012) also justifies her use of ethical theory on the basis that it

has a “normative dimension”, and Frith suggests that this prevents her from the “risk of adopting a position where anything goes” (p.199). Frith’s interpretation of ethical theory coheres with Walker’s feminist naturalism:

“Feminist ethical naturalism views moral theory as a ‘situated discourse’, a culturally specific set of texts and practices produced by individuals and communities in particular places and particular times.” (Walker, 2009, p.4).

Although Frith’s view of ethical theory may align with Walker’s, I have chosen not to use SB for this project on the basis that I do not want to be tied to any particular moral theory or set of principles, or try and align participants’ experiences to a specific moral framework. Furthermore, the work of much of feminist ethics is to show how moral theories fail to account for a multitude of moral experiences. Walker (2007) critiques ‘theoretical-juridical models’ of utilitarianism and contract theory because they present morality as a “compact, propositionally codifiable, impersonally action-guiding code within an agent, or a set of law-like propositions that ‘explain’ the moral behavior of a well-formed moral agent” (p.8). Rather than assuming the “*dominant* understandings of and in morality are the *best* ones; the critical project of much feminist ethics, naturalistic or not, is to show that often they are not” (Walker, 2009, p.4). Rather than enter debate regarding the place and role of ethical theory, I wanted to position the voices of nurses at the heart of this project and to be led by their experiences.

2.5.3 Reflexive Balancing

In response to criticisms of reflective equilibrium, Ives (2014) proposes a method of reflexive balancing which employs a quasi-moral foundationalism. Quasi-moral foundationalism is able to accommodate both the benefits of a coherentist framework – it remains broadly egalitarian as sets of beliefs can be introduced/ rejected based on coherence – and the benefits of foundationalism – enabling a foundation from which to build our coherent belief set. Quasi-moral foundationalism is based on Racine’s (2008) moderate moral foundationalism and allows for quasi-foundational beliefs – beliefs that are treated as epistemically privileged and posited as true for the purposes of moral enquiry. These epistemically privileged beliefs are derived from the empirical data and Ives (2014) labels them ‘boundary principles’. Importantly these beliefs are only treated as though they are epistemically privileged, they aren’t actually epistemically privileged and so they can still be altered, moved or replaced. Ives (2014) suggests that by deriving the boundary principles from the empirical data, this guards against researcher bias. The researcher cannot simply posit their own values as the boundary principles which would have the potential to bias the rest of the reflexive balancing process which he argues is a weakness of reflective equilibrium. However, in this project I deviate slightly from Ives’ method as I am going to treat my commitment to ‘core feminism’ as a boundary principle. I will come back to this point after explaining the method.

Once the boundary principles have been identified, ‘second-order judgments’ are then made and accepted as true if and only if they cohere with the boundary

principles and the rest of the system. Because the foundational beliefs remain changeable, reflexive balancing avoids the problem of historical accident and prejudiced beliefs that has been a criticism of reflective equilibrium. Building upon Quine's 'web of belief', Ives (2014) states that:

“Theories and beliefs in the centre are *relatively* insulated from challenge because they have demonstrated significant resilience and usefulness, but are nonetheless revisable if sufficient change occurs elsewhere in the system to make it necessary. When some new experience comes to light and a new belief is formed at the periphery, this new addition has to cohere with the rest of the system. If it cannot be made to cohere, it is either rejected or some change is made elsewhere in the system to accommodate it.” (p.307)

The boundary principles are then justified if they cohere with other posited beliefs in the system. As Ives (2014) highlights, the coherence of this system is challenged when recalcitrant experiences are identified:

“When a challenge is made to the existing coherent system, a moral problem is created, wherein the recalcitrant experience suggests to us that we ought to X, but our existing moral commitments suggest that we ought not to X.”
(p.308)

To determine which obligation is genuine, we need to either reject the conflicting boundary principle to accommodate the recalcitrant experience and work towards a new coherence, or reject the experience outright; the process required to achieve coherence is coined by Ives (2014) as 'reflexive balancing'. Similarly to reflective equilibrium, normative conclusions are justified by their coherence with the other boundary principles and second-order judgements but

the analytic process required to reach a conclusion is one that involves seeking disconfirming data and only conclusions that are supported by boundary principles are justified.

Ives (2014) states that reflexive balancing is not an entirely new method but instead lays bare a process that is similar to methods employed by for example, philosophers presenting their argument and counter-arguments in systematic steps, or qualitative researchers uncovering and justifying themes from their data. Essentially what makes reflexive balancing different is the prescriptively normative conclusions that can then be drawn, informing an account of how we should conceptualise and respond to moral distress.

The important variation between reflective equilibrium and reflexive balancing is that reflexive balancing is based on quasi-moral foundationalism, whereas reflective equilibrium rejects foundationalism. This means that reflexive balancing can overcome some key criticisms of reflective equilibrium, such as how one begins justifying and forming coherent beliefs without a foundation. To build this foundation, Ives (2014) suggests that boundary principles can be treated as though they are epistemically privileged. These would usually derive from the empirical data. However, for this project I am choosing to deviate slightly from this and I will treat the core feminist ideal of seeking to uncover and eradicate sexism and oppression as a boundary principle (Donchin and Purdy, 1999). “Core feminism” unites feminist theorists and commits them to the normative mandate of eradicating oppression (Donchin and Purdy, 1999,

p.3). I am justifying this deviation from Ives (2014) method on the basis that this principle is widely accepted and uncontroversial. It would be difficult to argue that it is ethically justifiable to continue the oppression of women and marginalised individuals. Secondly, although this may be a bias, I suggest it is a positive bias that aims for greater justice and equality, and is therefore coherent with the methodological biases which Scully (2010) suggests underpin feminist bioethics.

This commitment to the exploration of women's and oppressed individuals' moral experiences provides the starting point for this inquiry as I seek to explore critical care nurses' ethical experiences and to uncover any oppressive practices. The normative pull of this empirical bioethics projects is to provide ways to overcome oppressive practices and respond to moral distress. This underlying boundary principle upon which the rest of the project must cohere also provides the foundation from which to reject relativism. As Jaggar (1991) states feminist ethics is "incompatible with any form of moral relativism that condones the subordination of women [and marginalized individuals] or the devaluation of their moral experiences. It is neutral, however, between the plural and local understanding of ethics, on the one hand, and the ideal of a universal morality [so long as they do not] rationalize women's [or oppressed individuals] subordination or devalue their moral experience" (p.95).

Table 2 shows the steps that are required to follow the empirical bioethics method of reflexive balancing and the steps that I will take in this project.

Table 2: Steps required for Reflexive Balancing and Steps taken in this project

Steps Required for reflexive balancing*:	Steps taken in this project:
<p>1. Identification of a moral problem: the problem could be rooted in practical experience, engagement with empirical literature or from theoretical considerations.</p>	<p>1. The issue of moral distress was first identified through GM’s experiences in practice and key questions regarding the concept raised through engagement with the empirical and theoretical literature.</p>
<p>2. Disciplinary naïve inquiry into the problem: this can be achieved either by data gathering, engaging with social science literature, philosophical theoretical literature, legal cases, politics and policy, and must be undertaken reflexively. Aims are twofold:</p> <p>a) To uncover and explore from multiple perspectives, all the values that operate on the problem and try to find some basic value propositions which act as quasi-foundational boundary principles.</p> <p>b) To fully understand both micro and macro context of the problem, the way it is broadly conceived by the stakeholders, with the aim of uncovering recalcitrant experience.</p>	<p>2. Inquiry begins by systematically searching and reviewing the social science and theoretical/conceptual literature. Key questions raised and to be considered once empirical data gathered. Data gathered from stakeholders regarding their ethical experiences using feminist interpretive phenomenology. Reflexivity maintained throughout using a reflexive research diary.</p> <p>a) Data analysed using Van Manen’s six steps and quasi-foundational boundary principles determined.</p> <p>b) Stakeholders asked to describe ethical challenges and experiences of moral distress (micro), and how these systems could support them (macro). Participant data analysed individually and collectively to uncover any recalcitrant experiences.</p>
<p>3. Reflexive Balancing: identification of boundary principles (from 2a), followed by systematically</p>	<p>3. Boundary principles from commitment to ‘core feminism’ and those identified from analysis of the empirical</p>

<p>challenging those principles by actively searching for disconfirming data. If disconfirming data is found, the new boundary principle must be coherent with the others to be justified.</p>	<p>data challenged using disconfirming data, data from previous studies and theoretical literature. The data and theory that survives systematic challenges is used to form a coherent account of moral distress in UK nursing and how we ought to respond to it.</p>
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* Steps required for reflexive balancing is taken from Ives (2014).

2.6 Conclusion

Within this chapter, I have explained how feminist bioethics may be considered not only suitable but necessary for this project because feminist bioethics requires exploration of the social, political and power structures that affect ones lived experiences, and requires a commitment to social and political change (Scully, 2010). I also discussed the moral epistemology of feminist naturalism which is adopted by feminist philosophers and suitably underpins feminist bioethics. I discussed three consultative empirical bioethics methods and highlighted how reflexive balancing is capable of overcoming some of the challenges levelled at these approaches. Importantly, because reflexive balancing is a quasi-moral foundationalist method, it allows feminist bioethics core commitments to be posited as true and therefore provides a foundation for this project. In the next chapter, I will address the second step of reflexive balancing by systematically searching and reviewing the social science and theoretical/conceptual literature. At the end of chapter 3, I will formulate a plausible working definition of moral distress that can then be amended in light of the empirical findings. In chapter 4, I will return to discussion of methods as

I discuss the empirical methodology of feminist interpretive phenomenology and how it coheres with the rest of the project.

CHAPTER 3: LITERATURE REVIEW ⁴

3.1 Introduction

In the previous chapter, I introduced the underlying methodology and the empirical bioethics method of reflexive balancing to be used to combine empirical data and ethical theory to reach normative conclusions. As highlighted by Ives and Draper (2009), although there is nothing wrong with purely conceptual approaches to explore ethical problems, the way moral distress is understood and therefore responded to is rooted in healthcare practice and to discover more about it requires us to have ‘encounters with experience’ (Ives, 2008). The first of these encounters with experience will be through the lens of previous researchers reporting their findings, which comprises this literature review.

Within this review, I will explore the concept of moral distress by tracing the evolution of the term, paying particular attention to the way moral distress has been explored, defined and understood within the literature. The review will combine approaches from the disciplines of nursing and bioethics. Within nursing and medicine, there already exists the tradition of systematic reviews that aim to appraise in a minimally biased way the pre-existing literature related to a specific research question (Strech and Sofaer, 2012). However, systematic reviews in bioethics are a more recent development; Borry et al. (2005) and

⁴ A shortened version of this chapter was published in *Nursing Ethics* in 2017, and is listed along with other published work associated with this project after the author’s declaration.

Strech (2010) have argued that despite the ‘empirical turn’ in bioethics, there remains a lack of systematic analysis of both empirical and argument-based literature. Strech (2010) argues that empirical bioethics reviews of empirical literature ought to use some of the same steps employed within scientific literature reviews so that reviews are conducted in a systematic fashion, and studies are critically appraised for bias, reliability and validity. However, because empirical bioethics reviews may be asking slightly different questions to those found in the scientific literature, the process also needs to be responsive to an empirical bioethics context. To this end, this literature review comprises many of the systematic elements that are found within a traditional systematic review but with some notable differences (Strech et al., 2008). To maintain trustworthiness in this process I will thoroughly report each stage of this process so that it is duplicable and decisions transparent.

3.2 The Systematic Review Process

Strech et al. (2008) suggest a 7-step process for systematic reviews which covers the recommended formulation of search terms, selection of databases and relevance assessment. Up until relevance assessment (step 5), many of the steps resemble those found in a ‘traditional’ systematic review, for example as found in Coombs et al. (2017). However, because the aim is to gain an understanding of the *conceptual* development of moral distress, there is a greater degree of interpretation required in step 5. Steps 6 and 7 concern quality assessment, data analysis and presentation, of which Strech et al. (2008) recommend using a method which is appropriate to the studies under review, provided they are explicitly justified and explained. In this review, ‘Narrative

Synthesis' provided the overarching framework for steps 6 and 7 because this method accommodates synthesis of a range of different methodologies. Guidelines from Popay et al. (2006) provide direction for the process of narrative synthesis and recommend the use of different techniques such as conceptual mapping and textual description. In the next section I will describe how I carried out Streh et al's 7-steps, before going on to discuss the techniques for narrative synthesis.

1. Carefully defining the review question

Traditionally, systematic reviews within fields such as epidemiology and medicine are much more focused in their design because they are dealing with specific questions related to, for example, diseases or interventions; therefore the use of definitive review questions and search terms are appropriate (Streh et al., 2008). However, because this literature review is exploratory in nature, the review question remained broad and since the question did not concern clinical outcomes, it did not fit the traditional PICO (population, intervention, comparison, outcome) model. In these instances, Streh et al. (2008) suggest using the MIP (methodology, issues, participants) model but in this case only 'issues' and 'participants' were deemed relevant because I did not want to limit the retrieval of literature from one specific methodology. Table 3 shows the broad search question and the questions that will be considered when reviewing the literature. To gain a full understanding of previous conceptions of moral distress, the relevant literature was retrieved from across multiple disciplines, including nursing, medicine, allied healthcare professionals, education, and social work.

Table 3: The Review Questions

<p>Search question:</p> <p>What is ‘moral distress’ (<i>issue</i>) in nursing/ medicine/ allied healthcare professionals/ education/ social work (<i>participants</i>)?</p> <p>Broad review question:</p> <p>How is moral distress defined and understood in the empirical and theoretical literature?</p>
<p>Within this broad search question, the implicit questions for analysis consisted of:</p> <ul style="list-style-type: none">➤ How is moral distress explored within each particular body of literature?➤ How is moral distress conceptualised?➤ How does moral distress manifest itself?➤ How has moral distress been identified?➤ What are the effects of moral distress upon the relevant stakeholders?➤ Have relationships to other concepts been identified?➤ Have any suggestions been made regarding ways in which to mitigate the effects of moral distress?

2. Selection of the relevant databases

A broad range of databases were searched and these were chosen according to the specific discipline under exploration to increase the likelihood of relevant findings. These are listed along with the discipline specific search algorithms. Each discipline specific search was carried out separately on each database to increase the relevance of the results retrieved. After searching the discipline specific databases, searches were carried out on ethics databases to check for any papers that might have been missed, these were EthxWeb and

EUROETHICS. Tables 4-7 show examples of the search strategies used within these disciplines.

Table 4: The Search Strategy for Moral Distress in Nursing - an exemplar from MEDLINE

Facet 1	Facet 2
Moral Distress (MeSH) OR Moral Distress	Nurse (MeSH) OR Nurse OR Nurse\$ OR Nurs\$
A N D	
Total= 482	Total= 589812
Total= 351	

The databases searched for moral distress in nursing were: Ovid MEDLINE ® In-Process & Other Non-Indexed Citations, Ovid MEDLINE ® 1946-Present, PsycINFO ® 1967- Present, CINAHL ® Plus 1937- Present, EMBASE 1974-

2016 Feb 24 and British Nursing Index (BNI) 1994-Present. When trialed on Medline, this search yielded 351 results; this was deemed large enough to allow for a broad number of results whilst remaining manageable in terms of searching for relevance. When combined with other terms such as 'critical care' and 'intensive care', the search yielded only 82 results, which is too specific for a comprehensive understanding of the literature and therefore broader search terms were utilised.

Table 5: The Search Strategy for Moral Distress in Medicine - an exemplar from MEDLINE

Facet 1	Facet 2
Moral Distress (MeSH) OR Moral Distress	Doctor (MeSH) OR Physician (MeSH) OR Doctor\$ OR Physician\$ OR Medic\$ OR Medical Practitioner\$ OR MD OR Specialist
A N D	
Total= 482	Total= 2370318
Total= 192	

The databases searched for moral distress in medicine were: Ovid MEDLINE
 ® In-Process & Other Non-Indexed Citations, Ovid MEDLINE ® 1946-
 Present, PsycINFO ® 1967- Present, CINAHL, EMBASE 1974-2016 Feb 24.

Table 6: The Search Strategy for Moral Distress in Social Workers - an exemplar from MEDLINE

Facet 1	Facet 2
Moral Distress (MeSH) OR Moral Distress	Social Worker (MeSH) OR Social Work\$ OR Social Care OR Social Work (MeSH) OR Social Services (MeSH) OR Social Service\$ OR Social Welfare
<div style="border: 1px solid black; padding: 5px; display: inline-block;"> A N D </div>	
Total= 482	Total= 39374
Total= 5	

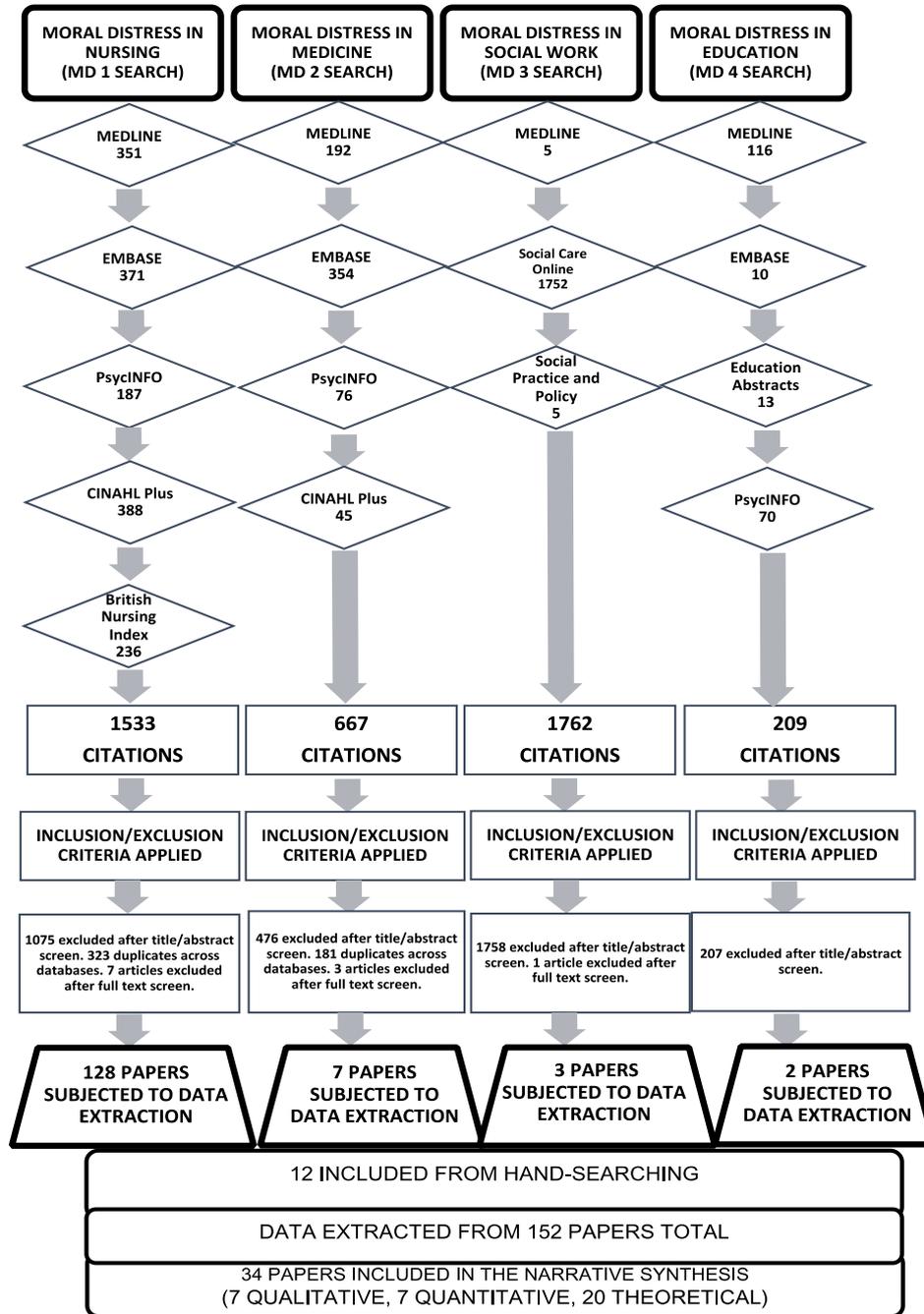
The databases searched for moral distress in medicine were: Ovid MEDLINE
 ® In-Process & Other Non-Indexed Citations, Ovid MEDLINE ® 1946-
 Present, Social Care Online and Social Policy and Practice Database (1890-
 Present).

Table 7: The Search Strategy for Moral Distress in Education - an exemplar from MEDLINE

Facet 1	Facet 2
Moral Distress (MeSH) OR Moral Distress	Education (MeSH) OR Learning (MeSH) OR Learning OR School\$ OR Schools (MeSH) OR Academ\$ OR Universit\$ OR Academies and Institutes (MeSH) OR Teach\$ OR Teaching (MeSH)
<div style="border: 1px solid black; padding: 5px; display: inline-block;"> A N D </div>	
Total= 482	Total= 1361245
Total= 116	

The databases searched for moral distress in education were Ovid MEDLINE ® In-Process & Other Non-Indexed Citations, Ovid MEDLINE ® 1946-Present, ERIC (EBSCO) 1966- Present, Education abstracts and PsycINFO ® 1967- Present.

Figure 2: PRISMA table of search results



3. Application of ancillary search strategies

In addition to electronic searching of relevant databases, hand-searching of the references of included studies was conducted to check for papers that could have been missed.

4. Development of a search algorithm

The concept of moral distress was first introduced in the 1980s but relevant work may have been published at, or before, that time, therefore no strict time limitations were imposed on the literature search. Reasonable attempts were made to access English language versions, but if none were available then a translator was not used and unpublished work was also not included. Search terms and the selection of relevant databases were guided by the discipline in which moral distress was being explored. It is recommended that databases are searched separately rather than together to increase the sensitivity of the search (King's College London, 2018) . The search terms remained the same, with MeSH terms varying slightly across databases. Examples of the search strategy from Medline are presented on pages 73-77. Figure 2 shows the PRISMA table of papers retrieved from each database, at which stage they were excluded, the number that underwent data extraction and those included within the narrative synthesis.

5. Relevance assessment of the retrieved references

Relevance assessment was carried out at two stages, as shown in Figure 3 (p.83). During the first stage, returned titles and abstracts were reviewed for eligibility against the inclusion/exclusion criteria (Table 8, p.84) and those deemed

irrelevant excluded. Relevant papers were then read in full and subjected to initial data extraction and quality review. The second stage of relevance assessment was then carried out, and only papers that (a) fulfilled the initial inclusion criteria, (b) were of sufficient methodological quality and (c) added to theory/concept development were then included within the narrative synthesis. Due to the large volume of papers identified, this criteria was necessarily stringent. The data extraction guide (Appendix 1) was developed from the guidance provided by Popay et al. (2006) and the review questions identified in Table 3 (p.72). This guide was used to structure the data extraction process and to guide assessment of methodological rigour. Some papers, such as Wilkinson (1987/1988), although methodologically flawed were still included in the review because it is a seminal paper that is important for conceptual development. These decisions were recorded in the data extraction tables to increase transparency (see Appendix 2-6 for examples of these).

Some papers retrieved discussed job related stress; these papers were excluded from the review because they did not have an ethical basis specifically and focused instead on occupational stress related issues. Several interventional studies were also retrieved in which the authors had measured moral distress pre-and post an intervention, such as an educational program. These papers focused on the evaluation of the intervention and did not explore the concept of moral distress and were therefore also excluded. Multiple commentaries, editorials and letters were excluded when reviewing abstracts due to the low quality of their conceptual analysis and lack of contribution to theory

development.

Up until this point, many of the steps described have followed those of a traditional systematic review. However, Strech et al. (2008) point out that the relevance assessment of reviews that incorporate data from diverse methodologies requires greater interpretation regarding relevance and consequently this step can be most susceptible to bias. To enhance trustworthiness, relevance assessment was documented and recorded in the data extraction tables (examples of which are in Appendix 2-6). By looking at these examples, the reader can gain understanding regarding why some studies, although deemed relevant for data extraction, were not then included in the narrative synthesis. Strech et al. (2008) state “to deserve the label *systematic*, reviews in empirical bioethics have to follow the guiding principles of transparency and systematisation within the crucial steps of the relevance assessment” (p. 474).

Figure 3: Flow Diagram detailing the Inclusion and Exclusion Process

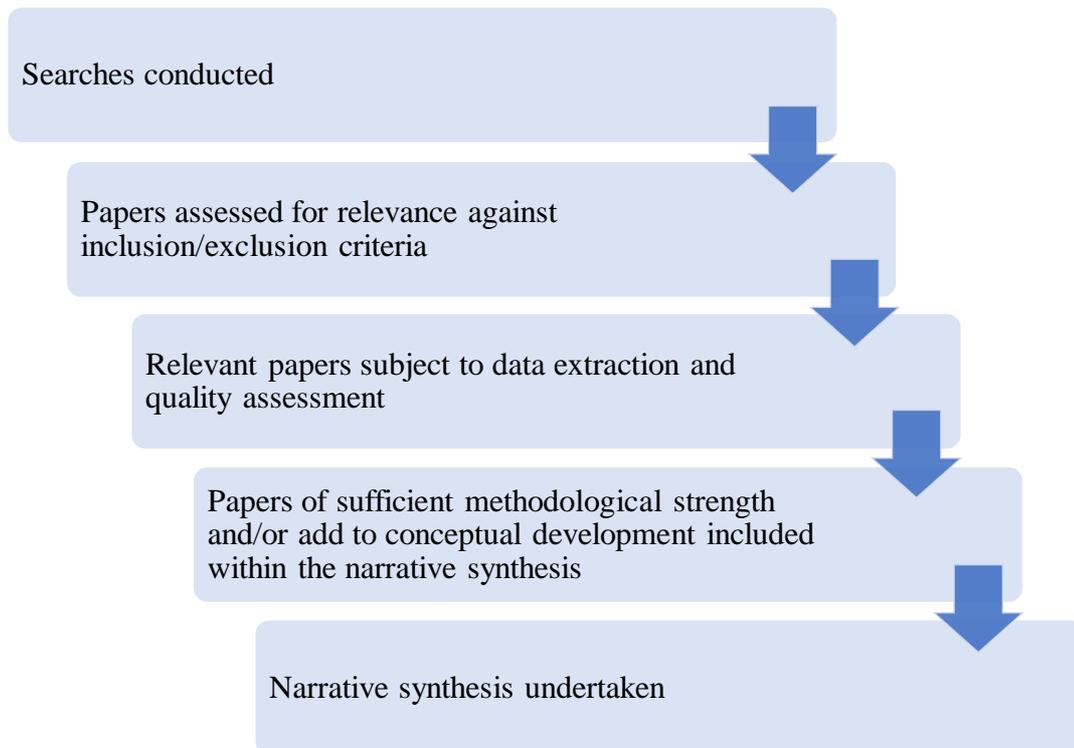


Table 8: Inclusion and Exclusion Criteria for Initial Review

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none">- Explores moral distress empirically.- Explores moral distress conceptually or theoretically.- Able to access an English language version.	<ul style="list-style-type: none">- Does not explore moral distress empirically.- Does not explore moral distress conceptually.- Moral distress is only mentioned in the discussion section.- Editorials, letters or commentaries discussing moral distress.- Intervention studies.- Unable to access an English language version.- Unpublished doctoral theses or dissertations.

6. Quality assessment of included studies

Quality assessment was undertaken on all papers that passed the first relevance assessment following the criteria in Table 8. Whitemore and Knafl (2005) note that quality appraisal in integrative reviews necessarily varies depending on the diversity of the included data, and as this review incorporates quantitative, qualitative and theoretical papers this process was complex. Quality assessment was conducted using a critical appraisal and data extraction guide (adapted from Popay et al. (2006) in Appendix 1) that was adapted for use with both empirical and theoretical papers to inform thinking about the robustness of each paper. They recommend tabulation as a tool for this initial stage, into which the basic summary information can be collated, such as study design, results, quality assessment and outcome measures. This was entered into the data extraction tables (Appendix 2-6) with a brief summary of the overall value of the research to the body of literature.

Whitemore and Knafl (2005) argue that in diverse reviews a historical research approach is appropriate for data evaluation and relevance assessment, which includes considering the authenticity, methodological quality and informational value of each paper. Methodological quality influenced the second stage of relevance assessment so that empirical papers deemed to be of poor quality were excluded (unless they also undertook theoretical analysis that contributed meaningfully to conceptual development). Conversely, papers judged to be methodologically strong but not providing conceptual insight were excluded (failing to meet the inclusion criteria on that basis). Methodological quality was

assessed according to whether the data collection method was suitable to the research question; evidence of rigor and trustworthiness; whether the conclusions followed from the findings and the strengths and limitations of the study. The theoretical, or argument based literature was judged upon the strength of the arguments, and the empirical literature was judged on methodological strength (Strech, 2008).

Following the title and abstract review, 152 papers underwent initial data extraction and 34 were chosen for inclusion in the narrative synthesis. Appendix 7 shows the data extraction for the papers included in the narrative synthesis.

7. Data analysis and data presentation

The method of 'Narrative Synthesis' provided the overarching methodological framework for this literature review. This methodology is appropriate because it allows for the inclusion and synthesis of a wide range of research designs. It has been critiqued as a method because of a lack of formal guidance (Snilstveit et al., 2012). However, Popay et al. (2006) have created guidance which consists of four main steps, and recommend tools and techniques for each step:

- a. Developing a 'theory of change'** in which the general theory behind the studies is described. There are no specific tools or techniques recommended for this phase, but Popay et al. (2006) argue that it is important to understand the overarching theory behind the studies under review. They provide the example of an intervention study, where

theory development would address the general understanding of how the intervention works, why and for whom. The theory underpinning this review is that there needs to be a clear understanding of what moral distress is to avoid confusion and build a rigorous empirical base. To develop this theory, the commonly proposed/used definitions of moral distress were tabulated (Table 9, p.89). Table 9 records the common definitions, by whom they were developed, the core elements of the definition and the authors that adopted the definition. This helped inform the structure of the narrative synthesis and understanding of conceptual development.

- b. Developing a preliminary synthesis of findings from the included studies.** Popay et al. (2006) recommend textual descriptions of studies, groupings, clusters and tabulation as ways to gather preliminary information on the included studies. This was carried out during initial data extraction, examples of which are presented in Appendix 2-6. Textual descriptions are provided of the key findings, strengths/limitations, and relationships between studies. Papers of sufficient methodological rigor and/or those that added to theory development are discussed and synthesised in section 3.3.
- c. Exploring relationships within and between studies.** Popay et al. (2006) recommend a number of statistical and conceptual methods for this element, such as funnel plots, frequency distributions, idea webbing and conceptual mapping. I developed a table of the highest scoring moral distress items according to the quantitative studies that used the Moral Distress Scale (Corley 1995), Moral Distress Scale-Revised

(Hamric et al., 2012), or the authors own version of the MDS or MDS-R, with mean scores and standard deviations noted. These were charted to help build a picture of the most commonly perceived causes of moral distress, frequency and intensity of each item and an insight into the reliability of the data. Aside from these quantitative data, other statistical methods were deemed unnecessary for this review because the aim is not to establish causation or prevalence but to gain a greater understanding of the phenomenon itself. Conceptual relationships between studies were explored and tabulated in data extraction tables (Appendix 2-6).

- d. Assessing the robustness of the synthesis.** Popay et al. (2006) discuss how this stage can be complex and requires judging the robustness of the primary studies included in the review, and the robustness of the synthesis itself. To enhance trustworthiness, I have reported each step in a transparent manner.

These steps are not intended to be followed in a linear fashion but instead form an iterative process whereby the reviewer can move between each stage in any direction (Popay et al., 2006).

In the next section, the most common definitions and the conditions required for moral distress will be discussed. Rather than discuss each definition in depth, the focus is on exploring the necessary/sufficient conditions that make up each definition, and I discuss these thematically.

Table 9: Common definitions of Moral Distress (chronological order)

No.	Reference	Definition	Necessary and/or sufficient conditions	Quoted In
1.	Jameton, 1984, p.6	“ <i>Moral distress</i> arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.”	<ul style="list-style-type: none"> - Moral judgement - Institutional constraint - Desired outcome may or may not be achieved 	<p>Astbury et al. (2015) Atabay et al. (2015) Austin et al. (2003) Eizenberg et al. (2009) Epstein and Hamric (2009) Fernandez-Parsons et al. (2013) Guthrie (2014) Laabs (2005) Lamiani et al. (2015) Ohnishi et al. (2010) Pauly et al. (2009) Peter et al. (2014) Redman and Fry (2000) Repenshek (2009) Stanley and Matchett (2014) Thomas and McCullough (2015) Trautmann et al. (2015) Vaziri et al. (2015) Whitehead et al. (2014)</p> <p>29 further authors attributed their definition to Jameton (1984) but provided a variation of his definition.</p>
2.	Wilkinson, 1987/88, p.16	“Moral distress is defined by the author as the psychological disequilibrium & negative feeling state experienced when a person makes a moral decision but does not follow through by	<ul style="list-style-type: none"> - Psychological effects - Moral decision - Desired outcome not achieved 	Lawrence (2011)

		performing the moral behavior indicated by that decision”		
3.	Jameton, 1993, p.542	“...a nurse experiences moral distress when the nurse makes a moral judgment about a case in which he or she is involved and the institution or co-workers make it difficult or impossible for the nurse to act on that judgment”	<ul style="list-style-type: none"> - Moral judgement - Institutional or coworker constraint - Desired outcome may or may not be achieved 	Edwards et al. (2013) Musto and Schreiber (2012)
4.	Corley, 1995, p.280	“Jameton defined moral distress as painful feelings and /or psychological disequilibrium caused by a situation in which (1) one believes one knows the ethically ideal action to take and (2) that one cannot carry out that action because of (3) institutionalized obstacles such as lack of time, lack of supervisory support, medical power, institutional policy, or legal limits.”	<ul style="list-style-type: none"> - Psychological effects - Knowledge of the right thing - Desired outcome not achieved - Institutional constraint 	Corley and Minick (2002) Taylor (2002)
5.	Corley et al., 2001, p.250	“Jameton (1984) defines as moral distress: the painful psychological disequilibrium that results from recognizing the ethically appropriate action, yet not taking it, because of such obstacles as lack of time, supervisory reluctance, an inhibiting medical power structure, institution policy, or legal considerations.”	<ul style="list-style-type: none"> - Psychological effects - Moral recognition - Desired outcome not achieved - Institutional constraint 	Range and Rotherham (2010) Wolf et al. (2016)
6.	Corley, 2002, p. 643	“Moral distress is the psychological disequilibrium, negative feeling state, and suffering experienced when nurses make a moral decision and then either do not or feel that they cannot follow through with the chosen action because of institutional constraints.”	<ul style="list-style-type: none"> - Psychological effects - Moral decision - Desired outcome not achieved - Institutional constraints 	Wilson et al. (2013)
7.	Hanna, 2004, p.74	“Moral distress includes but exceeds the unique situation of the knowledge of right action constrained by	<ul style="list-style-type: none"> - Overarching term - Psychological effects 	

		institutional barriers. As an umbrella category that contains the other two, moral distress could accompany moral uncertainty or moral dilemma.”	<ul style="list-style-type: none"> - Institutional constraint - Can occur with knowledge of the right action of during a moral dilemma or moral uncertainty 	
8.	Kälve mark et al., 2004, p.1082-3	“Traditional negative stress symptoms that occur due to situations that involve ethical dimensions and where the health care provider feels she/he is not able to preserve all interests and values at stake.”	<ul style="list-style-type: none"> - Psychological effects - An ethical problem - Compromised values 	Abbasi et al. (2014) de Veer et al. (2013) Førde and Aasland (2008) Nejadsarvari et al. (2015) Sporrong et al. (2005) Sporrong et al. (2006)
9.	Peter and Liaschenko, 2004, p.221	“if moral agency is defined as the capacity to recognize, deliberate/reflect on, and act on moral responsibilities, in order to experience moral distress, an agent is required to possess at least some autonomy in recognizing and reflecting upon moral concerns. Yet on the other hand, an agent’s autonomy must be at least somewhat constrained in acting upon the very moral responsibilities he/she understands him/herself to have. This apparently irresolvable contradiction is moral distress.”	<ul style="list-style-type: none"> - Moral agency/ moral autonomy - Constraint on moral agency/ moral autonomy - Irresolvable contradiction 	
10.	Corley et al., 2005, p.382	“Jameton (1984), who defined it as painful feelings and/or the psychological disequilibrium that occurs when nurses are conscious of the morally appropriate action a situation requires but cannot carry out that action	<ul style="list-style-type: none"> - Psychological effects - Awareness of the right action a moral belief - Desired outcome not achieved 	Manara et al. (2014)

		because of institutionalized obstacles.”	- Institutional obstacles	
11.	American Association of Critical Care Nurses, 2006, p.1	<p>“Moral distress occurs when:</p> <ul style="list-style-type: none"> • You know the ethically appropriate action to take, but are unable to act upon it. • You act in a manner contrary to your personal and professional values, which undermines your integrity and authenticity.” 	<ul style="list-style-type: none"> - Moral judgement - Unspecified constraint - Act contra to personal and professional values - Moral integrity compromised - Authenticity compromised 	McClendon and Buckner (2007)
12.	Nathaniel, 2006, p.421	<p>“Moral distress is pain affecting the mind, the body, or relationships that results from a patient care situation in which the nurse is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgment about the correct action, yet, as a result of real or perceived constraints, participates, either by act or omission, in a manner he or she perceives to be wrong.”</p>	<ul style="list-style-type: none"> - Psychological effects - Physical effects - Aware of a moral problem - Acknowledges moral responsibility - Makes a moral judgment - Constraint or perceived constraint - Desired outcome is not achieved 	Cavaliere et al. (2010) Dumouchel et al. (2015) Rushton et al. (2015) Maluwa et al. (2012)
13.	Canadian Nurses Association, 2008, p.6.	<p>“Ethical (or moral) distress arises in situations where nurses know or believe they know the right thing to do, but for various reasons (including fear or circumstances beyond their control) do not or cannot take the right action or prevent a particular harm. When values and commitments are compromised in this way, nurses’ identity and integrity as moral agents are affected as they feel moral distress.”</p>	<ul style="list-style-type: none"> - Moral judgement or moral belief - Constraint - Values compromised - Commitments compromised - Moral identity compromised - Moral integrity compromised 	Harrowing and Mill (2010) Molloy et al. (2014) Wojtowicz and Hagen (2014) Wojtowicz et al. (2014)
14.	McCarthy and Deady, 2008, p.254	<p>“...an umbrella concept that captures the range of experiences of individual who are morally constrained.</p>	<ul style="list-style-type: none"> - Overarching term - Constraint 	Nuttgens and Chang (2013) Peter and Liaschenko (2013)

		Generally speaking, when individuals make moral judgments about the right course of action to take in a situation, and they are unable to carry it out, they may experience moral distress. In short, they know what is the right thing to do, but they are unable to do it; or they do what they believe is the wrong thing.”	<ul style="list-style-type: none"> - Moral judgment - Desired outcome is not achieved 	Sunderland et al. (2015) Woods et al. (2015)
15.	McCarthy, 2013, p.1	“Moral distress is an umbrella concept that describes the psychological, emotional and physiological suffering that may be experienced when we act in ways that are inconsistent with deeply held ethical values, principles or moral commitments.”	<ul style="list-style-type: none"> - Psychological effects - Physiological suffering - Compromised ethical values, principles or moral commitments 	
16.	Jameton, 2013, p.297	“Moral distress- a common experience in complex societies- arises when individuals have clear moral judgments about societal practices, but have difficulty in finding a venue in which to express concerns.”	<ul style="list-style-type: none"> - Moral judgment - Affects society as a whole - Unable to express concerns - Desired outcome not achieved 	
17.	Hamric and Wocial, personal communication, October 24, 2013 in Hamric, 2014, p. 457	“Moral distress occurs when an individual’s moral integrity is seriously compromised, either because one feels unable to act in accordance with core values and obligations, or attempted actions fail to achieve the desired outcome.”	<ul style="list-style-type: none"> - Moral integrity compromised - Desired outcome not achieved, despite efforts. 	
18.	Barlem and Ramos, 2015, p.612	“...the feeling of powerlessness experienced during power games in the micro-spaces of action, which lead the subject to a chain of events that impels him or her to accept imposed individualities, have his or her resistances reduced and	<ul style="list-style-type: none"> - Constraint on moral action - Constraint on moral deliberation - Constraint on one’s ability to advocate 	

		few possibilities of moral action; this obstructs the process of moral deliberation, compromises advocacy and moral sensitivity, which results in ethical, political and advocational inexpressivity and a series of physical, psychical and behavioural manifestations.”	<ul style="list-style-type: none"> - Reduction of moral sensitivity - Feelings of powerlessness - Physical, psychological and behavioral effects 	
19.	Fourie, 2015, p.97	“Moral distress is a psychological response to morally challenging situations such as those of moral constraint or moral conflict, or both.”	<ul style="list-style-type: none"> - Psychological effects - Morally challenging situation - Can occur during moral constraint or moral conflict 	
20.	Campbell et al. 2016, p.6	“One or more negative self-directed emotions or attitudes that arise in response to one’s perceived involvement in a situation that one perceives to be morally undesirable.”	<ul style="list-style-type: none"> - Self-directed psychological effects - Morally undesirable situation 	

3.3 Narrative Synthesis

3.3.1 Introduction

Despite the increase in empirical research regarding moral distress, many nursing scholars have noted the lack of conceptual clarity which has complicated attempts to study it (McCarthy and Deady, 2008; Pauly et al., 2012). Within this review, I will trace the evolution of the concept of moral distress by exploring its proposed necessary and sufficient conditions. I will identify areas of conceptual tension and agreement amongst these definitions and the discussion will be structured around the necessary and/or sufficient conditions proposed in each definition. These conditions are identified from the most commonly cited definitions (recorded in Table 9) which, I argue, have contributed most to conceptual development. Implicit within this approach is an acceptance of the classical theory of the structure of concepts. According to Margolis and Laurence (2011), the classical theory suggests that concepts have a definitional structure and are made up of smaller, simpler concepts that can be found in the language of necessary and sufficient conditions. They use the famous example of a ‘bachelor’; the concept ‘bachelor’ is made up of the necessary and sufficient conditions of ‘unmarried’ and ‘man’, and identifying these conditions allows one to understand the concept ‘bachelor’. They state that “concept acquisition can be understood as a process in which new complex concepts are created by assembling their definitional constituents” (Margolis and Laurence, 2011). Similarly, I aim to provide an understanding of moral distress through analysis and discussion of the necessary and/or sufficient conditions that make up each key definition in order to inform a working

definition of moral distress. This working definition will then be further revised in light of nurses lived experiences and a model presented in chapter 7 that captures moral distress and its relation to associated concepts. This approach differs, therefore, from philosophical ‘armchair’ conceptual analysis in which concepts are tested using counterexamples and thought experiments only, because empirical data is also incorporated into the definitional and conceptual development.

The language of necessary and sufficient conditions is commonly used in philosophy to define and explain connections between concepts and causality; offering a helpful way to conceptually examine moral distress. Mackie (1965) used the example of a house fire to explain the relationship between necessary and sufficient conditions, pointing out that there is no single necessary and sufficient condition for a house fire, but there are some necessary conditions for a fire to occur (such as heat, oxygen, combustible material) and there are various groups of conditions that are sufficient together but not necessary (a match for example can cause a fire, but so too can a lighter). Importantly, there cannot be a house fire unless these necessary and sufficient conditions (sources of ignition, combustible material, oxygen) are met.

To use a different illustration, there are certain conditions, such as frailty, immobility or poor nutrition, associated with the increased likelihood of developing a pressure ulcer. None of these, however, are necessary or sufficient conditions for a pressure ulcer; they are only factors that increase the likelihood of an ulcer forming when the necessary and sufficient conditions are met. There

is one condition that is both necessary and sufficient for a pressure ulcer, and that is the presence of continued pressure on the skin. It is necessary because a pressure ulcer cannot occur without it, and it is sufficient because that is the only thing needed to form a pressure ulcer. Whilst the language of necessary and sufficient conditions is useful for delineating conditions required for a definition and concept, it must be noted that this approach has also been critiqued. Brennan (2017), for example, raises questions regarding the truth function of the conditional statement (if p then q) which is entailed when one adopts the standard theory of necessary and sufficient conditions. Brennan (2017) highlights how there is debate regarding what is actually meant by 'necessary' and 'sufficient', and notes that these terms themselves suffer from a lack of definitional clarity. Within this thesis however, the truth function is not employed, by which I mean that the language of necessary and sufficient conditions is used for clarity of meaning rather than for logical entailment.

That said, one of the main challenges of defining moral distress is that, as we shall see, moral distress tends to be conceptualised in terms of the conditions in which it arises- for example 'moral distress occurs when conditions X and Y are met'. This leaves us with questions regarding the paradigmatic, temporal and causal nature of moral distress (Tigard, 2017). By the end of this thesis, I will have provided my interpretation and explanation regarding what it means to experience moral distress, the circumstances in which it occurs, and the temporal and causal nature of moral distress.

The starting point of this inquiry is Jameton's (1984) definition in which moral distress is framed in terms of the conditions in which moral distress arises. For Jameton, moral distress occurred when (i) a moral judgement has been made and (ii) there are institutional constraints that prevent that moral judgement from being acted on. On this account, the presence of 'constrained moral judgement' is both a necessary and sufficient condition of moral distress. It is necessary because moral distress cannot occur without it, and it is sufficient because nothing else is needed for moral distress to occur. Literature on moral distress since then has either:

- (i) Accepted this account of moral distress, as based on a single necessary and sufficient condition and defined moral distress in terms of that condition.
- (ii) Challenged the necessity and/or sufficiency of that single condition.
- (iii) Suggested adding other necessary or sufficient conditions.
- (iv) Added to the necessary and sufficient conditions a range of specific causes of those conditions.

Definitions of moral distress are, therefore, a relatively confused and complex bundle of necessary and sufficient conditions, causes and effects, which this chapter aims to unpick.

3.3.2 Moral Judgement

Within this section, I focus on one of Jameton's suggested necessary and sufficient conditions for moral distress: moral judgement. When Jameton (1984) first introduced the term, he differentiated between moral distress, moral uncertainty and moral dilemmas, stating that they were three distinct ethical problems in healthcare:

“Moral uncertainty arises when one is unsure what moral principles or values apply, or even what the moral problem is” (Jameton, 1984, p.6).

“Moral dilemmas arise when two (or more) clear moral principles apply, but they support mutually inconsistent courses of action” (Jameton, 1984, p.6).

According to Jameton (1993), the nurses he encountered described experiencing moral distress when they had made a moral judgement but were unable to act upon it. Jameton (1984,1993) therefore aligned moral distress with moral judgement from the inception of the term. However, this understanding of moral distress has been critiqued by Fourie (2015) and Campbell et al. (2016) as unacceptably narrow; if the nurse must have made a moral judgment then this implies moral distress cannot occur during a moral dilemma or moral uncertainty because these situations are often characterised by indecision. This criticism can be applied to many of the definitions suggested, with the exceptions of those by Kälveborn et al. (2004), Wocial and Hamric (Hamric 2014) and Fourie (2015), because moral judgement/awareness/belief does not feature as a necessary or sufficient condition in their definitions (see Table 9).

Other authors, much like Jameton (1984, 1993), seem to stipulate that moral judgement is a necessary/sufficient condition of moral distress but they have contributed to conceptual confusion because they have used different terminology. For example: ‘moral judgment’, ‘moral decision’, ‘moral belief’, ‘conscious of’ or ‘awareness’ (see definitions 1, 2, 3, 4 5, 6 and 10, 11, 12, 13 in Table 9). The different phrasing creates epistemological ambiguity because, for example, a belief seems to be a stronger epistemic claim than an awareness. However, the authors of these definitions failed to critically engage with the implications of altering the terminology of this condition which suggests that despite changing the wording they accept the basic premise: moral agents only experience moral distress when they have formed a judgement regarding the right thing to do. This interpretation, that the difference between them is one of expression, rather than of meaning, is justified on the basis that such an omission suggests they have failed to appreciate the difference between each epistemological statement. Whether we can, therefore, accept ‘moral judgement’ as a necessary condition for moral distress will depend on what we mean by ‘moral judgement’, and regarding this, the literature is unclear.

Hanna (2005) proposes a different understanding of moral distress as a “type of interior recoil, interior aversion, or internal withdrawal from that which is perceived to produce harm to an observed or objectively known good.” (p.115)

Hanna (2005) states the critical attribute is ‘perception’ of an objective good, which, she argues is culturally unique, objectively good and God-given. Here, Hanna (2005) seems to be making two very different suggestions as she

introduces both the idea of moral judgement as a perception which seems to be weaker than a judgement, but the perception is of an objective good which suggests the possibility of moral truth and moral knowledge. Hanna (2005) seems to be suggesting that moral distress occurs when one perceives a moral truth which is a much stronger claim than Jameton's. Nonetheless, the notion of perception is more akin to Corley's fourth definition (definition 10 in Table 9). In this formulation, Corley et al. (2005) states there is an *awareness* or *perception* of the morally correct action or value at risk.

I am, however, inclined to go further and argue that in fact an awareness or perception of the right thing may not even be a prerequisite for moral distress. Rather, it is only necessary when determining the *cause* of distress. For example, a newly qualified nurse might feel distressed about the fact that the patient she is caring for is positive for human immunodeficiency virus (HIV) but has not told his wife; however, she might not recognise that her distress is ethically rooted and therefore does not label her experience as moral distress. The nurse explains how she feels to a colleague who has more knowledge regarding healthcare ethics. The colleague could legitimately state that the nurse feels a type of distress that is ethically rooted and therefore label the distress, moral distress. Determining the cause of her distress as ethically rooted and recognising her experience as moral distress might help her to address it and seek further information regarding the ethical and legal issues of the patient's decision to withhold this information. This could in turn alleviate her feelings of distress. Yet in this hypothetical example, the nurse does not necessarily recognise the issue as moral, yet she still feels distressed and it seems legitimate

that such an experience could still be labelled moral distress. The use of an analogy might help to illustrate this point; let's take the example of a breast cancer diagnosis. If a woman discovers a lump in her breast and goes to the doctor for further investigation, during the time in which she waits for the diagnosis she would still be regarded as having cancer, only it has not yet been confirmed and diagnosed. In the same way, the nurse above experienced moral distress, but wasn't yet aware of the moral origin of her distress. This is not to say that every nurse who feels distress is experiencing *moral* distress, but if the distress is found to have a moral origin, then it may be reasonable to label it moral distress. Hanna (2004) makes a similar distinction: "by assuming knowledge of the right action always preceded an event, moral distress was defined by a single quality of antecedent knowledge (the quality of certainty), rather than by its core word 'distress'" (p.74). Arguably, the moral agent does not need to have made a moral judgement or even be aware of the moral problem to experience moral distress.

We are left with the following key questions regarding the inclusion of moral judgement as a necessary/sufficient condition of moral distress.

1. What is meant by 'moral judgement'?
2. Is 'moral judgement' a necessary and/or sufficient condition for moral distress?

At the end of each section, I will highlight key questions that have been raised from my analysis of the literature. These questions will then be used to inform

data collection and analysis. Some of these questions will be answered with my empirical findings, some will remain unanswered and others will be used to challenge the empirically informed account of moral distress that I suggest at the end of chapter 5. I will therefore return to some of these questions again in chapter 7 when I systematically challenge my account of moral distress.

3.3.3 Moral Dilemmas and Uncertainty

Fourie (2015) argues that Jameton's inconsistent and interchangeable use of the concepts 'moral dilemma' and 'moral conflict' indicates that he accepts a commonsense understanding of moral dilemmas. On the commonsense view, a moral dilemma occurs when one is faced with a difficult moral decision but, with enough thought, is able to identify the morally correct action. Whereas the standard philosophical view is that a dilemma occurs where there are two competing and equally strong obligations that cannot both be met (Fourie, 2015).

On the face of it, the difference between the two may not seem important but, Fourie (2015) argues, if Jameton views these concepts as interchangeable it forces the conclusion that moral distress is mutually exclusive to *both* moral dilemmas and moral conflicts; this makes Jameton's definition narrower still. Fourie (2015) uses Jameton's example of 'postoperative exercise' to illustrate her point. Jameton (1993) describes a situation where a mentally competent patient declines to exercise postoperatively; the nurse explains to the patient the benefits of exercise, yet the patient still declines. According to Jameton (1993), in this example, the nurse is presented with a dilemma between autonomy (the

patient's wishes not to exercise) and beneficence (the nurse knows the exercise will benefit the patient's recovery). Fourie (2015) argues that Jameton's example is a moral conflict rather than a dilemma because there is a morally correct course of action (although Fourie (2015) does not make the morally preferable action known). This example shows that Jameton (1993) views moral dilemmas and moral conflicts as interchangeable. Therefore, if we accept Fourie's interpretation then Jameton's definition of moral distress runs the risk of eliminating not only moral dilemmas and moral uncertainty as causes of moral distress but also moral conflicts. Intuitively this does seem troubling since one might feel that distress, of a moral nature, could occur during any one of these ethical problems.⁵

⁵ It is noted that there is continuing philosophical debate regarding the existence of 'genuine' moral dilemmas. Gowans (1987) provides an anthology of the key contributors to this debate but two of the main positions that often arise in debate are between the rationalists who tend to deny genuine moral dilemmas on the basis that morality is based on reason, and it is irrational and indeed illogical to be required to carry out two mutually exclusive acts; and those such as Bernard Williams who use phenomenological arguments for the existence of moral dilemmas. Williams suggests that feelings of regret and loss indicate that some moral requirements do not cease to exist just because they cannot be fulfilled. The purpose of this thesis is not to argue for the existence of genuine moral dilemmas, however due to the underlying methodology of feminist bioethics, because lived experience is taken as a source of epistemic value, the fact that people do seem to experience moral dilemmas does have force. Therefore, the accepted position within this thesis is that of Williams.

Many authors of the empirical and theoretical literature have failed to acknowledge or recognise the implications of Jameton's narrow definition. For example: Ohnishi et al. (2010) and Brazil et al. (2010) define moral distress according to Jameton (1984) yet state that moral distress is widely experienced in response to an ethical conflict; Wiegand and Funk (2012) state moral distress is itself a type of ethical conflict; and Walsh (2010) describes moral distress as "the feelings and experiences that result from a moral conflict"(p.746) and attributes this to Jameton (1984). Whilst Hilliard et al. (2007) state that their aim is to explore moral distress but they seem to instead focus on the ethical conflicts experienced by trainee doctors. If, however, we chose to refute Fourie's argument these studies are not problematic.

Fourie's argument rests upon her assumption that in Jameton's example of postoperative exercise there is a morally preferable course of action. One might, as Fourie (2015) suggests, defend Jameton by arguing that his example of a moral dilemma was simply not robust enough. Jameton could therefore maintain that moral conflicts and dilemmas are two distinct moral problems and that moral distress occurs during moral conflicts, but not during moral dilemmas. If this is the case, it may be that Jameton is upholding his belief that moral distress only occurs during moral judgements because it may be more readily accepted that an agent has made a moral judgment during a moral conflict (the conflict being over the judgement made) rather than a moral dilemma (which is characterised by indecision).

Nonetheless, there is empirical work that also suggests Jameton's

differentiation between moral distress and moral dilemmas does not hold true in lived experience. For example, Redman and Fry (2000) reviewed five of their previous papers regarding ethical conflicts in different areas of nursing to explore how they were experienced. The authors found that many ethical conflicts were experienced as both moral dilemmas and moral distress, and that a significant number of ethical conflicts were experienced as moral distress (Redman and Fry, 2000).

Similarly, Källemark et al. (2004) conducted focus groups with healthcare professionals in Sweden and found that those interviewed (nurses, doctors, auxiliary nurses, medical secretaries and pharmacy staff), perceived moral distress as occurring during moral dilemmas where the healthcare professionals did not know the ethically correct course of action. They proposed the following definition of moral distress:

“Traditional negative stress symptoms that occur due to situations that involve ethical dimensions and where the health care provider feels she/he is not able to preserve all interests and values at stake.”

(Källemark et al. 2004, p. 1082-3)

Källemark et al. (2004) conclude that, “ethical judgements rarely refer to an individual person knowing certainly what is right or wrong. The process of ethical decision-making is much more complex.” (p.1083) Indeed, moral uncertainty may arise because the agent does not know which values to apply, or there could be a conflict in values. Källemark et al. (2004) concluded that

exploration of moral distress ought to focus more on the *context* of moral dilemmas rather than individual's moral beliefs.

Interestingly, in a later paper Jameton (2013) urges bioethicists concerned with moral distress to move beyond moral distress to larger global issues of climate change, and states "...moral distress expresses a decision point, a moment of emotive immobility, where ambivalence needs to be resolved toward a choice. Once the choice is made and action is undertaken, the psychological elements of distress tend to diminish." (p.303) This statement seems to undermine his previous conceptions of moral distress, as he suggests that moral distress occurs exactly when one is forced to choose between two actions but struggles to do so, for example during a moral dilemma.

These conceptual issues highlight the importance of further empirical research to examine theoretical issues. Fourie (2015) argues that the power of her argument lies in the fact that many researchers have failed to acknowledge these distinctions between moral distress, moral conflicts, moral dilemmas and moral uncertainty because they are problematic and difficult to draw.

Due to the differing views in the literature, the following key questions will be raised again in chapter 7:

3. Does moral distress occur in cases of moral conflict, moral uncertainty, moral dilemmas, or all three?

In the next section, I will discuss whether constraint is a necessary and/or sufficient condition for moral distress.

3.3.4 Constraints as Causes: Institutional, Personal and Perceived

Hanna (2004) and Pauly et al. (2012) argue that Jameton's definition frames moral distress as a purely occupational issue, arising because of institutional barriers or constraints. This resulted in decades of research that, assuming constraint to be a necessary condition of moral distress, explored the institutional constraints that cause moral distress rather than critically analysing the phenomenon itself. In the following sections, the external/institutional constraints of policies and practices, the hierarchy, epistemic injustice and ethical climate will be discussed. This will be followed by a brief discussion of the internal constraints.

(i) The Moral Distress Scale

Corley (1995) developed the first quantitative scale to explore moral distress; The Moral Distress Scale (MDS). The first MDS started as a 32-item scale asking participants to score from one (low) to seven (high) the degree to which each item was perceived to cause moral distress intensity and frequency. The MDS was found to have good test-retest reliability ($r=0.86$ ($p<0.01$)) and excellent internal consistency (Cronbachs $\alpha = 0.93$ ($p<0.01$)), which indicates the MDS is a reliable instrument (Corley 1995).

Corley (1995) combined Jameton's and Wilkinson's (1987/88) definitions to create a broad conception of moral distress which formed the theoretical basis

of the MDS:

“Jameton defined moral distress as painful feelings and /or psychological disequilibrium caused by a situation in which (1) one believes one knows the ethically ideal action to take and (2) that one cannot carry out that action because of (3) institutionalized obstacles such as lack of time, lack of supervisory support, medical power, institutional policy, or legal limits.”

(Corley, 1995, p.280)

This formulation contains the following suggested conditions for moral distress: moral belief, psychological effects, desired outcome not achieved and institutional constraint. However, the only condition under study in the MDS itself is constraint, with some references to the psychological effects. As shown in Table 9, although Corley varied her definition of moral distress many of the conditions remained the same, the exception being the condition of ‘moral judgment’.

The MDS has been adopted by numerous researchers and used in many different countries (Canada, Iran, Italy, Japan, Jordan, New Zealand, Sweden, Turkey, USA) and clinical settings (medical and surgical intensive-care, oncology, general acute areas, paediatric, psychiatric) to measure the frequency of which certain constraints are perceived to be experienced, and the intensity of distress caused amongst nurses, physicians, respiratory therapists, healthcare students and non-healthcare students. Due to the popularity of the MDS as a research tool, the importance of institutional constraints as a cause of moral distress has persisted throughout the empirical literature.

Other instruments have also emerged that claim to measure moral distress, such as the Ethical Dilemmas in Nursing Questionnaire (DeKeyser Ganz and Berkovitz, 2012), the Moral Distress Questionnaire (de Veer et al., 2013) and the Ethics Stress Scale (Dumouchel et al., 2015). The MDS has also undergone multiple modifications with the aim of improving its relevance to the various settings and samples. However, as highlighted by Hamric (2012) many of these studies have not adhered to rules of psychometric testing, or factor analysis and have failed to adequately test the validity of their instruments. For example, Davis et al. (2012) set out to identify whether nurses' ethical beliefs impact moral distress levels. The authors argued that because their study was exploratory they did not want to use an established instrument but instead developed their own. However, the instrument was not tested for reliability nor was there evidence of factor analysis testing; the authors only discuss receiving content validity from four professionals and a group of nurses.

Additionally, it is also often unclear which definition of moral distress is being adopted by researchers to underpin their work. For example, many of the authors have used Jameton's definition, variations on Jameton's definition, Wilkinson's (1987/88), or any one of Corley's definitions to define and measure moral distress. However, as highlighted by the variety of necessary/sufficient conditions that make up these definitions, it is clear they represent different interpretations of moral distress and therefore it is not clear which formulation of moral distress is being tested. Hamric (2012) highlights how "valid measures require a tight linkage between the concept and the items developed for the

measure. It is clear that, at present, multiple measures exist which measure different concepts.” (p.44) The lack of clarity between the definition and the actual scale used is therefore problematic and gives cause to doubt the validity, or at least the comparability, of the findings. Johnstone and Hutchinson (2015) argue that “the very presentation of given issues in the moral distress research scales already pre-code and interpret the situations presented as involving ‘moral distress’ thus priming respondents to accept both the existence and incidence of moral distress as a ‘reality’ in their practice.” (p.6). Indeed, the MDS does not invite participants to critically engage with the phenomenon itself and instead assumes the existence of moral distress and the validity of that particular conception of moral distress.

Recently, Hamric et al. (2012) revised Corley’s MDS, developing a shorter 21-item scale to measure intensity and frequency of moral distress, with 6 parallel versions- the Moral Distress Scale-Revised (MDS-R). The parallel versions enable moral distress to be measured in adult and paediatric settings amongst nurses, doctors and other healthcare professionals. Nurses and doctors highest scoring items were very similar which indicates similar constraints cause moral distress for both groups (Hamric et al., 2012). Allen et al. (2013) also used the MDS-R and advanced registered nurse practitioners and respiratory therapists reported the highest levels of moral distress, which could indicate that moral distress affects those in the middle of the hierarchy: those able to make some independent decisions, but ultimately responsible for carrying out the decisions of those senior to them. Whitehead et al. (2014) found that both direct and non-direct care providers, such as social workers, chaplains and pharmacists

reported similar levels of moral distress on the MDS-R to nurses.

The MDS-R however suffers the same criticisms of the MDS and does not encourage participants to critically engage with the phenomenon under study. The studies that use the MDS and MDS-R are numerous but because they do not add to definitional development, I will not go into depth regarding their findings. However, it may be useful to have a brief overview of the findings. In Box 1, I provide a brief summary of the quantitative papers, definitions, measures used, and findings.

Box 1: Summary of Quantitative Findings

Of 69 quantitative and 3 mixed-methods studies exploring moral distress:

- 19 used Corley's MDS (or a paediatric version obtained via personal communication from Corley)
- 10 used the MDS-R, 24 used adapted versions of either the MDS or MDS-R
- 19 used other instruments
- Of those, 9 used Jameton's verbatim definition, 20 used a variation on his definition but attributed it to Jameton, 8 mentioned more than one definition but did not commit to any and 9 papers did not discuss the definition used.

The four most commonly cited items using the MDS and MDS-R reported to cause the highest intensity and frequency of moral distress, and thus constrain participants were:

- 'Carry out physician's orders for unnecessary tests and treatments.'
- 'Follow the family's wishes to continue life support even though it is not in the best interest of the patient.'
- 'Work with levels of nurse staffing that I consider 'unsafe.''
- 'Work with physicians who are not as competent as the patient care requires.'⁶

⁶ The wording of each item differs slightly between the MDS and MDS-R, I present the items according to the MDS.

Corley (1995) developed the items in the MDS based on Wilkinson's (1987/88) findings, and the similarities between Wilkinson's original findings and the highest scoring moral distress items in the quantitative studies (presented below) are striking. Wilkinson (1987/88) reported that moral distress occurred where moral problems and constraints prevented nurses from carrying out their moral decisions and the cases most often mentioned were:

- “(1) prolonging life (e.g. inability to obtain ‘No Code’ orders and aggressive/heroic treatments of dying patients);
- (2) performing unnecessary tests and treatments (especially on terminally ill patients);
- (3) situations involving lying to patients;
- (4) incompetent/inadequate treatment by a physician.” (p.20)

The similarities in these results are remarkable, especially when considering the time span and various settings in which these studies have been carried out. This could indicate that the same issues continue to be problematic, or that healthcare professionals need to be asked about different constraints or ethical issues that occur. Nonetheless, it is worth highlighting that the MDS is based on Wilkinson's results and received content validity from Wilkinson and Jameton and therefore it captures a potentially limited understanding of moral distress, which has been perpetuated through its further usage. As further definitions of moral distress have been suggested, the MDS has not adapted to reflect this, as it is still designed to capture constraints only.

Fourie (2015) suggests that one way to understand moral distress is by delineating between different types of moral distress, for example ‘moral-constraint distress’. It may be argued therefore that the MDS is measuring this one particular type of moral distress and does not capture a broader understanding of moral distress.

(ii) Ethical Climate

The exploration of external/ institutional constraints continued with exploration of perceived ethical climate of institutions. Again, it was Corley et al. (2005) who led the way, surveying nurses with a revised 32-item MDS and an Ethical Environment Questionnaire (EEQ), developed by McDaniel (1997), and other researchers used the Hospital Ethical Climate Scale (HECS) by Olson (1998). Correlations were found between higher moral distress scores and negative perceptions of hospital or unit ethical climate. In Corley et al. (2005), the EEQ, with weak statistical significance, correlated to higher moral distress intensity scores ($p=0.038$). The lowest scoring items on the EEQ were: ‘I am involved in deliberations addressing ethics concerns about my work’ and ‘there is an ethics committee in this organisation available to me if I need it.’ Corley et al. (2005) hypothesised that these low scoring items could suggest ways to reduce moral distress. This finding is repeated in Whitehead et al. (2014) where more positive perceptions of ethical climate were associated with lower moral distress scores ($p<0.0001$) and in Hamric and Blackhall (2007), Silén et al. (2011) and Hamric et al. (2012).

Although these findings are undoubtedly useful because they provide the initial steps to highlighting links between moral distress and institutional climate, Musto and Rodney (2015) argue that they do not illuminate the complexity between individual moral agency, the institution's interests and resulting moral distress. Musto and Rodney (2015) argue that capturing the complexity of moral distress can only be achieved by developing a relational understanding of moral distress in which "individual agent's actions [are] nested within layers of structural contexts that are infused with complex power dynamics." (p.3) Arguably, the use of scales and quantitative measures such as the MDS and HECS are not flexible enough to gather this rich information.

Similarly to Musto and Rodney (2005), Peter and Liaschenko (2004) suggest reframing moral distress so that it captures relational complexity:

"if moral agency is defined as the capacity to recognize, deliberate/reflect on, and act on moral responsibilities, in order to experience moral distress, an agent is required to possess at least some autonomy in recognizing and reflecting upon moral concerns. Yet on the other hand, an agent's autonomy must be at least somewhat constrained in acting upon the very moral responsibilities he/she understands him/herself to have. This apparently irresolvable contradiction is moral distress." (p.221)

In a theoretical paper, Peter and Liaschenko (2013) argue that moral distress is a response to constraints on nurses' moral identities, responsibilities and relationships. Constraint is still considered a necessary condition of moral

distress, but rather than highlighting particular causes, they emphasise the effect on the moral agent. Adopting a feminist ethics framework, the authors emphasise the social connectedness of morality and the belief that moral knowledge is born out of shared moral experiences. They argue that the institutions in which nurses' work create constraints on nurses' moral identities when they are prevented from carrying out their core values. They use the example of poor staffing and increased workload, highlighting how these constraints can prevent nurses from forming relationships with their patients which inhibits their ability to provide holistic care.

Peter and Liaschenko (2013) argue that:

“Without the support of institutions, nurses cannot fulfill their professional responsibilities, revealing the connected nature of moral agency and the vulnerability all health care professionals have within complex networks of care delivery. The moral distress experienced by nurses in these instances is again a reaction to a violation of trust and constraints to moral agency because of nurses' anticipation that the institutions in which they work will place quality of care above other values, such as efficiency.” (p.341)

Exploring the relationship between moral distress and ethical climate represents another step towards exploring the interconnectedness between institutions and the moral agents working within them. However, as suggested by Musto and Rodney (2015), it is likely that we will need to go beyond the use of quantitative scales to capture the nuances of power relations which may affect experiences

of moral distress. In a qualitative paper, Dzung et al. (2016) found that junior doctors in the US experienced moral distress, often during end-of-life care, and specifically cited the hierarchy as a constraint on their moral agency. It is likely that institutional constraints, ethical climate and hierarchy will differ according to job role and therefore cause different experiences of moral distress.

(iii) Internal Constraints

In addition to external constraints, internal or personal constraints have also been highlighted as a cause of moral distress, although they have received very little attention within the quantitative literature, with some exploration in the qualitative. Epstein and Hamric (2009) identify internal constraints as self-doubt, lack of assertiveness, socialisation to follow orders, perceived powerlessness and lack of understanding. It is likely that this lack of exploration is due to moral distress being predominantly conceptualised as rising from external constraint on action rather than uncertainty from within. Although Barlem and Ramos (2015) do theorise that the power play in various 'micro-spaces' can create internal constraints which impede one's ability to deliberate about moral issues.

(iv) Epistemic Injustice

Another suggested form of constraint on nurses' moral agency, identified by Reed and Rishel (2015), is epistemic injustice. They argue that moral distress occurs because often nurses aren't informed of treatment decisions or reasoning behind decisions, and their views often aren't incorporated into decision-making or interdisciplinary discussions, creating 'epistemic inequality' in the

workplace. Reed and Rishel (2015) argue that because nurses are one of the most trusted groups of healthcare professionals (citing (Riffkin, 2014), with UK data also mirroring this (The King's Fund, 2015)), a moral burden is placed upon them. Nurses are in a position of trust, working closely with patients and families, and yet are not privy to full disclosure regarding treatment decisions, and must instead convey and enact decisions made by others. Reed and Rishel (2015) argue that when nurses are questioned by patients and families regarding treatment decisions without full knowledge they feel moral distress. In their example, the nurse thinks the right thing to do is to fully inform the patient/family, however they are constrained by their uncertainty regarding the reasoning behind treatment decisions and previous discussions with the family. Reed and Rishel (2015) argue that this is a result of epistemic injustice, "a wrong done to someone specifically in their capacity as a knower" (Fricker 2007, p.2). If the nurse was fully informed, they could disclose information and would not experience moral distress.

The concept of epistemic injustice is based upon the work of Fricker (2007), who argues there are two kinds of epistemic injustice: testimonial injustice and hermeneutical injustice. Testimonial injustice can result in either a credibility excess or a credibility deficit, resulting in the speaker receiving either more credibility than they ought to, or less. Reed and Rishel (2015) suggest testimonial injustice occurs in nurse-physician interactions in the context of end-of-life decisions where nurses' professional opinions are undermined and ignored despite their knowledge and experience, resulting in moral distress. Whereas hermeneutical injustice is experienced by groups of people, and

Fricker (2007) suggests it is a structural identity prejudice. Fricker (2007) defines hermeneutic injustice as, “the injustice of having some significant areas of one’s social experience obscured from collective understanding owing to a structural identity prejudice in the collective hermeneutical resource” (p.155). Fricker (2007) suggests that hermeneutic injustice arises because of a collective lack of understanding which prevents the knower from understanding their own social experience. Reed and Rishel (2015) suggest that nurses experience hermeneutic injustice as decreased self-worth, a lack of confidence in their own knowledge and an inability to make sense of and articulate their experiences with patients. Both forms of epistemic injustice can occur because of discrimination against one’s social identity and may affect nurses in particular because they are below doctors in the medical hierarchy. They argue that “this hinders development of intellectual courage, selfhood, and well-being, as well as impoverishes disciplinary knowledge overall.” (Reed and Rishel, 2015, p.242).

Reed and Rishel (2015) stress that a hierarchical healthcare structure remains firmly in place, with the physician still considered the leader of the team in which communication to other team members flows downwards. There is evidence in the literature that the traditional medical hierarchy continues to pervade healthcare decisions which in turn creates moral distress. Peter et al. (2014) explored nurses’ moral knowledge in cases of perceived aggressive care and identified four common narratives. In one of these narratives: “privileged medical understandings and responsibilities”, participants described how medics dominated healthcare decisions with very little consideration for the

opinions of nurses, resulting in the protraction of aggressive care. One participant described a situation in which cardiopulmonary resuscitation (CPR) had been failing for some time with an elderly gentleman in accident and emergency:

“This doctor would insist in putting in a jugular line, putting in an arterial, pumping him up with inotropes. He would insist on that. And, all of us mumbling, saying this is not right, he should let him die. And I approached the doctor and I told him listen, doctor I don’t think that we should. I don’t think this is right for this patient. He’s going to die. Why can’t you let him die in peace? And boy, there was an uproar. He attacked me personally. He said I didn’t have the knowledge.” (Peter et al., 2014, p.467)

This example suggests that, in some cases, the knowledge and opinion of medics may still be perceived as superior to nurses, which causes moral distress. Peter et al. (2014) conclude that although nurses discussed ‘knowing’ the right thing to do, their narratives explored the inherent complexities in implementing this, one of those being privileged medical understanding. McCarthy and Deady (2008) hypothesise that nurses’ position in the hierarchy of decision-making exposes them to greater moral grief (although this term is not defined, it is thought to be a type of moral injury). This suggests that to mitigate moral distress, we may need to find a way to negotiate between nurses’ own personal sense of right and their ability to influence or contribute to moral decision-making.

(v) **Removing Constraint from Moral Distress?**

Although many researchers have cited constraint as a necessary condition of moral distress, others have critiqued this interpretation. Musto and Rodney (2015) suggest that researchers have committed an epistemic fallacy by “conflating the *measures* of moral distress with what moral distress actually *is*” (p.6). Similarly, Fourie (2015) argues that because Jameton (1984, 1993) has stipulated both cause (constraint) and effect (distress), he has created a compound definition of moral distress which excludes other causes of moral distress. Musto and Rodney (2015) argue that moral agents do not always experience moral distress in situations where they are constrained and that empirical research reveals a multitude of situations that cause moral distress, and multiple responses to moral distress that are affected by various factors. Musto and Rodney (2015) argue that this indicates there is much more to understand about the concept and to gather this information, researchers ought to explore the structures: the ‘moral contexts’ in which agents experience moral distress, and the interplay between them. They argue that quantitative studies fail to “capture the complexity of moral agents acting in dynamic contexts” (Musto and Rodney, 2015, p.7). This suggests more empirical research is required that can capture these dynamic contexts.

Fourie (2015) suggests moral distress should be ‘decoupled’ from constraint and that moral distress instead be re-classified into different forms of distress, such as ‘moral-constraint distress’ or ‘moral-conflict distress.’ The following key questions regarding the relationship between moral distress and constraint will be taken forward to be discussed again in chapter 7.

4. Are external/institutional or internal/perceived constraints necessary and/or sufficient conditions of moral distress?
5. Do other factors, such as the institution, team, or unit contribute to, or cause moral distress?

3.3.5 The Psychological and Physical Effects of Moral Distress

Hanna (2004) argues that “moral distress includes but exceeds the unique situation of knowledge of right action constrained by institutional barriers” (p.74). She argues, further, that previous empirical research, rather than providing narratives of preoccupation with moral certainty, tell of personal anguish which imply the core issue is ‘distress’, and Jameton’s definition fails to account for this. Indeed, on Jameton’s account, there is no necessary affective component to moral distress, and moral distress could occur without anyone feeling distressed, all that is needed is a moral judgement that cannot be acted upon.

Wilkinson (1987/1988) was the first to explicitly incorporate the psychological effects of moral distress into the definition, suggesting that an agent experiencing moral distress feels “psychological disequilibrium and [a] negative feeling state” (p.16). Although this is supported in her findings, Wilkinson does not clarify whether this newly proposed definition is developed from the empirical findings or rather a presumption upon which she builds. Wilkinson (1987/88) carried out face-to-face interviews with nurses ($n=24$), thirteen of whom had previously worked in acute care and eleven currently

worked in acute care. From the interviews, Wilkinson describes ‘indicators’ of moral distress that are perceived as contributing to, or influenced by moral distress, one of which is described as ‘feelings.’ Wilkinson found that moral distress caused feelings of anger, frustration and guilt, produced in response to one’s moral choice being thwarted, and suggested that moral distress was damaging to nurses’ ‘wholeness’ as they reported loss of self-esteem. Wilkinson (1989) argued that Jameton’s definition refers only to the *causes* of moral distress, not the *effects* and thus incorporated both into her definition.

In response to this, Jameton (1993) suggested that moral distress could be divided into initial and reactive moral distress, arguing that he had captured initial distress and Wilkinson (1987/88) had captured reactive distress:

“Initial distress involves the feelings of frustration, anger and anxiety people experience when faced with institutional obstacles and conflict with others about values.

Reactive distress is the distress that people feel when they do not act upon their initial distress.”

(Jameton 1993, p.544)

Reactive distress has since been linked to the concept ‘moral residue’. Epstein and Hamric (2009), referring to Webster and Baylis’s (2000) conception of moral residue, suggest that reactive distress is the lasting effects of moral distress, caused by repeatedly compromising one’s deeply held values (Webster and Baylis, 2000).

Epstein and Hamric (2009) possibly support the distinction between initial and reactive moral distress because it emphasises the division between moral and psychological distress. They argue that moral distress only occurs when one's core values have been violated and psychological distress does not necessarily indicate this. They use the example of under-staffing to highlight their point; they argue that under-staffing does not create moral distress, and only creates psychological distress because core values are not violated and ethical obligations can be upheld. However, this seems to be a rather simplistic understanding of the issue of under-staffing which fails to account for the compromised position it can place nurses in. When having to choose between prioritising patients, who may potentially be in seriously life-threatening positions, this essentially becomes an issue of distributive justice. The argument put forward by Epstein and Hamric (2009) implies that if one cannot sufficiently prove that one's core values have been violated, then one's experience cannot properly be labeled moral distress. However, unsafe staffing is reportedly one of four highest scoring constraints believed to cause moral distress, numerous cited as causing the most intense and frequent cause of moral distress in the MDS and MDS-R.

Wilkinson (1987/88) also explored the effects of moral distress on patient care. Some participants perceived the effects of moral distress as damaging to patient care and felt moral distress caused them to avoid patients. This is supported in a later study by Varcoe et al. (2012) in which nurses felt that moral distress caused them to make mistakes and spend less time with patients. However, in both studies, participants also reported trying to mitigate these effects by

spending more time with patients. However, Wilkinson (1987/88) suggests participants were in denial of the effects moral distress could have on patient care because it posed a threat to their personal and professional self-image. Peter and Liaschenko (2013) also suggest that moral distress threatens nurses' identity. They suggest that the nursing identity is socially constructed and associated with being a virtuous caregiver, and because moral distress prevents nurses from enacting their ideals it thwarts their ability to be virtuous. Accepting failures in patient care would entail a failure to uphold their self-image which is potentially too difficult to accept (Wilkinson, 1987/88).

The qualitative literature captures much of the psychological and physical effects of moral distress. Wiegand and Funk (2012) reported that nurses discussed feeling frustration, anger, sadness, psychological/physical exhaustion, helplessness, distress and depression. Whilst Hanna (2004) described the physical effects of moral distress as anguish, sleeplessness, nausea, migraines, gastrointestinal upset, tearfulness and physical exhaustion.

Other studies have explored the correlations between moral distress and other potentially related concepts such as burnout (Meltzer and Huckabay, 2004, Ohnishi et al., 2010, Shoorideh et al., 2015) and compassion fatigue (CF) (Maiden et al., 2011, Mason et al., 2014). It has been hypothesised that due to the psychological and physical similarities between burnout, CF and the effects of moral distress that they are likely related in some way (Maiden et al., 2011; Rushton et al., 2015). Burnout is characterised as increased feelings of exhaustion (emotional exhaustion), a negative cynical attitude towards care

recipients (depersonalisation) and dissatisfaction with oneself (reduced personal accomplishment) (Maslach and Jackson, 1981, Kilfedder et al., 2001). Whilst CF has been described as a “state of emotional, physical, social and spiritual exhaustion leaving the individual fatigued, overwhelmed, helpless, and hopeless about one’s situation or life, causing a pervasive decline in the person’s desire, ability and energy to feel and care for others” (Maiden et al., 2011, p.340).

Maiden et al. (2011) explored the relationship between moral distress (defined according to Jameton (1984)), CF and medication errors. Critical care nurses ($n=205$) completed a questionnaire on moral distress using the 38-item MDS from Corley et al. (2001), and a 30-item Professional Quality of Life Scale to measure CF, both of which had been used previously and shown good reliability. They found a statistically significant moderate relationship between moral distress and CF ($p<0.001$), showing that higher moral distress scores were correlated with higher perceptions of CF. This suggests that the relationship between these concepts requires further exploration.

Rushton et al. (2015) explored several factors believed to affect the retention and turnover of nursing personnel: burnout, moral distress, stress, resilience, meaning and hope. The authors surveyed nurses working in ‘high-intensity settings,’; this was decided upon patient acuity, patient characteristics and staffing ratios. The survey consisted of six scales to measure each factor; four of the six scales had been used previously and shown good reliability. Both moral distress and resilience were statistically significantly correlated to all

three aspects of burnout (emotional exhaustion, depersonalisation, personal accomplishment), indicating that where moral distress scored highly, so did burnout, whilst greater resilience was correlated with lower scores. The authors concluded that moral distress predicted burnout, whereas greater resilience mitigated it (Rushton et al., 2015). Whilst it is acknowledged that measuring these factors quantitatively and based on self-report may be problematic, such findings are important indicators of potential relationships and further areas of study.

Nonetheless, following Wilkinson's introduction of the psychological distress component into the definition of moral distress, it has come to be accepted by many as a necessary condition of moral distress. Indeed, appealing to a commonsense understanding of the term 'moral distress', it seems obvious that any distress causally associated with a 'moral event', such as a moral dilemma or moral uncertainty is, *ipso facto*, moral distress. Although commonsensical, this does not necessarily clarify anything, and the problem remains of defining what a 'moral event' is and of determining what the causal association between the 'moral event' and the distress looks like. However, some researchers warn that focusing on the psychological/ physical effects of moral distress risks overlooking the ethical element and reduces moral distress to a mere psychological phenomenon (Epstein and Hamric, 2009).

Several questions remain regarding the extent to which the psychological/physical effects of moral distress ought to be incorporated into the definition of moral distress. Whilst they are undoubtedly an important

element of the concept, listing all the numerous effects of moral distress may serve to blur the concept further rather than clarify it. The following questions will be taken forward into the empirical phase:

6. To what extent are the psychological or physical effects considered a necessary/sufficient condition of moral distress?
7. Is there evidence to support a distinction between initial and reactive moral distress?
8. What is the relationship of moral distress to CF and burnout?

3.3.6 Threat to Moral Integrity

In 2006, the American Association of Critical-Care Nurses (AACN) released a position statement claiming that the inability to act upon personal and professional values undermines integrity and authenticity, and this is core to the experience of moral distress. The AACN stated:

“Moral distress occurs when:

- You know the ethically appropriate action to take, but are unable to act upon it.
- You act in a manner contrary to your personal and professional values, which undermines your integrity and authenticity.”

(American Association of Critical Care Nurses, 2006, p.1)

This distinction between professional and personal values does not feature in previously suggested definitions of moral distress, despite some discussion in the literature.

More recently, Wocial and Hamric (in Hamric, 2014) also suggested that moral integrity is central to moral distress, and that compromised moral integrity causes an emotional distress response such as avoidance, frustration and anger:

“Moral distress occurs when an individual’s moral integrity is seriously compromised, either because one feels unable to act in accordance with core values and obligations, or attempted actions fail to achieve the desired outcome” (personal communication, Wocial and Hamric, October 24, 2013 in Hamric, 2014, p.457)

Within this section, I will discuss the relationship between moral integrity and moral distress, and suggest that although there does seem to be a relationship between the two concepts, integrating moral integrity into a definition of moral distress risks conflating two poorly defined concepts which, rather than adding to conceptual clarity, in fact adds to conceptual blurring. I will also discuss the relationship between professional and personal values and suggest that moral integrity could provide a vital theoretical link between the two.

Hamric (2014) highlights how the process of moral decision-making inevitably requires compromise due to the diverse moral values and opinions that often come into play and therefore one of the most difficult challenges when moral distress occurs is attempting to protect everyone’s moral integrity. Hamric (2014) suggests that when one cannot uphold their core values and beliefs that their moral integrity is compromised, causing moral distress.

Thomas and McCullough (2015) explore what they term ‘ethically significant’ moral distress, differentiating this from the psychological effects of moral distress. The authors argue that they are only concerned with: “the intellectual, not psychological, experience of making a judgment that one is not able, to differing degrees, to act on one’s moral knowledge.” (p.108) Thomas and McCullough (2015) developed a taxonomy of ‘ethically significant’ moral distress and argue that this can be divided into six philosophical categories: *challenges* to professional and personal integrity, *threats* to professional and personal integrity, and *violations* to professional and personal integrity. They argued that these categories place different values under threat and thereby cause the various degrees of moral distress within their taxonomy. This account is consistent with Wilkinson’s (1987/88) cause and effect model, and frames moral distress in terms of necessary cause (threat to moral integrity) and necessary effect (psychological distress). Arguably, however, the use of moral integrity does not bring any clarification, as it is itself an ambiguous concept, that may include all the sufficient causes hereto discussed.

Thomas and McCullough (2015) used Beauchamp and Childress (2013) definition of moral integrity, characterising it as “soundness, reliability, wholeness, and integration of moral character,” and more specifically “objectivity, impartiality, and fidelity in adherence to moral norms.” (p.40) Hardingham (2004) for whom threat to moral integrity is also a necessary condition of moral distress, suggested an interpretation of integrity from the political philosopher, Larry May. Hardingham (2004) states that moral integrity

refers to “a wholeness in the relationship between our actions and our values and beliefs...about a certain conception of our self as being a consistent whole.” (p.129) May argues that professionals are socialised into their sense of obligation and that personal and professional integrity therefore depend upon society. Moral integrity, like moral distress, can be understood in a variety of ways. This highlights the problem with introducing the notion of moral integrity to moral distress; rather than clarify the definition of moral distress, it merely defers the problem.

Hardingham (2004) and Thomas and McCullough’s (2015) conceptions of moral integrity can however, serve to emphasise the relationship between professional and personal values, suggesting they are connected through one’s moral integrity. In a review of the literature, Hanna (2004) discussed the relationship between personal and professional values in her exploration of moral distress and questions whether it is even possible to separate the two. Hanna (2004) argued that due to Jameton’s preoccupation with the institutional causes of moral distress, conflict between one’s personal and professional beliefs, and their effect on moral distress had been ignored in the literature.

Undoubtedly, there are times when healthcare professionals will feel their professional and personal values conflict. Beauchamp and Childress (2013) cite the example of healthcare professionals who hold religious commitments to uphold the sanctity of life, yet at the same time participate in the withdrawal of life-sustaining treatments. Such acts might sustain professional integrity whilst violating personal integrity, and it is logical to conclude could cause the

psychological effects often associated with moral distress. Indeed, Webster and Baylis (2000) argue that seriously compromised moral integrity irreversibly alters oneself, stating that “personal integrity is ineluctably linked with personal identity.” (p.223) The extent to which personal and professional values play a part in causing moral distress warrants further exploration.

The literature certainly seems to suggest there are some instances of moral distress where integrity is violated, however the question remains whether this ought to be incorporated into the definition of moral distress. The inclusion of another conceptually problematic condition potentially confuses moral distress further. Nonetheless, this discussion once again raises important questions that will be raised again in chapter 7 to challenge my account of moral distress:

Key Questions:

9. What is moral integrity and is violation of moral integrity a necessary and/or sufficient condition of moral distress?
10. Does conflict between personal and professional values cause moral distress?

3.3.7 Desired Outcome Achieved

Wikinson (1987/88) introduced the notion that agents who experience moral distress are unable to enact their moral judgement. Prior to this, Jameton (1984) only stated that it was “nearly impossible” for the agent to carry out their moral judgement, thereby leaving it unclear regarding whether the desired outcome is achieved or not. Whereas, Wocial and Hamric incorporated the notion that the

agent had tried but failed in their definition of moral distress, stating that “attempted actions fail to achieve the desired outcome.” (Hamric, 2014 p. 457)

These differences are noteworthy because they suggest that it is not the outcome that causes moral distress but the process. Nathaniel’s (2006) findings also support this as nurses reported that when experiencing moral distress, they didn’t always feel they had participated in moral wrongdoing nor that their values were always violated. Nathaniel (2006) didn’t suggest altering the moral distress definition but instead suggested a new theory of ‘moral reckoning’. According to Nathaniel (2006) moral reckoning involves a situational bind, in which “serious and complex internal conflicts within individuals and tacit or overt conflicts [occur] between nurses and others, all having moral or ethical overtones.” (p.428) Nathaniel (2006) suggests that moral distress signifies a ‘jumping-off’ point and moral reckoning captures the various stages that occur during morally difficult situations.

Webster and Baylis (2000) discuss incorporating situations in which one has been unable to achieve their desired outcome into an account of moral distress. They suggest that moral distress occurs when one “fails to do what one believes to be the right course of action (or fails to do so to one’s satisfaction) for one or more of the following reasons: an error of judgement, some personal failing (for example, a weakness or crimp in one’s character such as a pattern of ‘systemic avoidance’), or other circumstances truly beyond one’s control.” (p.218) Adopting this position would mean that for moral distress to occur, in addition

to any other suggested necessary/sufficient conditions, the desired outcome of the moral agent must also not have been achieved.

Due to uncertainty within the literature, the following key questions will be used to inform data collection and analysis:

11. Must the agent have tried, and failed, to experience moral distress?
12. Can an agent be said to experience moral distress because of a personal failing or character flaw?

3.3.8 The Redundancy of Moral Distress

The concept of moral distress is not without its critics. Johnstone and Hutchinson (2015) argue that the entire concept ought to be abandoned on the basis that it undermines the process of moral deliberation by perpetuating the notion that nurses' moral judgements are justified. They argue that moral distress, as it is currently understood, (according to Jameton (1984, 1993)), risks nurses failing to nurture the skills required for ethical discussion and damaging their integration into moral decision-making because of the "assumed rightness of [their] moral judgements" (Johnstone and Hutchinson, 2015). Indeed, Weinberg (2009) highlights how Jameton's conception of moral distress fails to acknowledge the possibility that there might not even be a 'correct' course of action.

However, there is also evidence to suggest that moral distress may signal someone who is more attuned to moral issues. Woods et al. (2015) administered

the MDS-R to a random sample of nurses in New Zealand and found that the younger nurses (who also reported receiving more ethics education) reported higher levels of moral distress compared to older nurses. This could indicate that ethics education makes one more morally sensitive to ethical issues and therefore more susceptible to moral distress. Russell (2012) argued that moral sensitivity may be a prerequisite for experiencing moral distress. Conversely Woods et al. (2015) findings could indicate that older nurses, who are potentially more experienced, have developed coping mechanisms and are therefore able to better manage their experiences of moral distress, subsequently reporting lower levels.

Johnstone and Hutchinson (2015) also critiqued moral distress on the basis that it perpetuates the notion of nurses as powerless victims, which Paley (2004) argues is a favourite meta-narratives of nursing: nurses as victims that are under-appreciated, oppressed and unable to implement change (Paley, 2004). I am wary of perpetuating the powerlessness narrative and this is one reason for the chosen methodology of feminist bioethics. Whilst a primary aim of feminist bioethics is to give voice to those who are marginalised, a secondary aim is to implement and affect change.

Johnstone and Hutchinson (2015) also highlight how all healthcare professionals are to an extent constrained and therefore question whether nurses ought to be regarded as a 'special case' (p.9). Arguably, if moral distress were decoupled from constraint or disassociated with preformed moral judgements, these critics could potentially be assuaged.

Nonetheless, there are three important reasons why moral distress should not be regarded as a redundant concept. Firstly, the popularity of the concept should not be ignored. The fact that so many researchers have chosen to further explore this topic highlights, I believe, a deep resonance. Moral distress speaks to nurses because it communicates a deeply felt problem; whether or not this problem is one of constraint, compromised integrity, psychological distress, or all three, remains to be seen, but there is something compelling about the concept. Secondly, as a nurse, I have myself experienced many of the issues raised in the literature and these experiences sparked my interest in the concept.

The third reason I am convinced that moral distress is not a redundant concept are the experiences already found in the empirical literature. The experiences cited in the qualitative literature refer to deeply unsettling experiences that warrant further exploration. In addition to these reasons, empirical literature exploring moral distress in a UK context is sparse and there may be important differences between the UK context and elsewhere. Rather than abandon the concept, I suggest that we ought instead to aim to achieve conceptual clarity.

3.3.9 The Changing Narrative of Moral Distress

In a study reported in Peden-McAlpine et al. (2015) and Traudt et al. (2016), 19 experienced critical care nurses who had self-identified as skilled and comfortable during end-of-life care were interviewed. The authors found that moral distress did not arise as a theme and they found this surprising considering many other studies reported end-of-life care as contributing to experiences of

moral distress. The nurses in Traudt et al. (2016), who had an average of 17 years critical care experience, reported feeling a strong sense of moral agency, felt accountable for their actions, possessed ‘moral imagination’ (meaning they could empathise and appreciate the values of others), and perceived a ‘moral community’ in which they viewed themselves as an integral part of the decision-making process. The authors highlighted how the nurses in this study seemed to feel able to navigate ethically difficult scenarios. The key question is, as Rushton and Carse (2016) highlight, what makes these nurses different to those who do experience moral distress in similar scenarios?

Commenting on Traudt et al. (2016), Rushton and Carse (2016) applaud the changing moral distress narrative, from the powerlessness nurse to one in which the nurse is able to thrive within a moral community, bolstered by ethical competency, likely authority and able to enact their moral agency. Rushton and Carse (2016) suggest that frequent use of the MDS has perpetuated the powerlessness narrative because it has restricted inquiry into moral distress, and does not encourage exploration of support strategies. This changing narrative highlights how although moral distress may affect a large proportion of nurses, some are able to navigate potentially morally distressing scenarios. They conclude that to overcome moral distress, we must be committed not only to clarifying what it is, but to identifying strategies that reduce it (Rushton and Carse, 2016). The final two key questions raised from the research conducted by Peden-McAlpine et al. (2015) and Traudt et al. (2016) will be considered during the next phase of the project in data collection and analysis.

Key Questions:

13. Why do some nurses experience moral distress whilst others do not?
14. What strategies are currently used or could be used to mitigate moral distress?

3.4 Conclusion

The aim of this narrative synthesis was to identify the way moral distress has been defined and conceptualised within the empirical and theoretical literature. I have shown there are multiple definitions of moral distress, many of which are made up of various necessary/sufficient conditions which change the meaning of the concept and have caused conceptual confusion.

To summarise, Jameton (1984, 1993) suggested that moral judgement and constraint were necessary and sufficient conditions for moral distress. However, this 'narrow' conception of moral distress has become inconsistent for several reasons. Firstly, a range of accounts which purported to be consistent with Jameton used the term 'moral judgement' inconsistently, referring (in different accounts) to apparently different cognitive states of varying epistemic strength. This results in confusion about whether moral judgement is required for moral distress to occur. Although this might be simply an inconsequential difference of expression rather than meaning, it is problematic because consistent and unambiguous language is vital when trying to understand a complex concept.

Secondly, Fourie (2015) highlighted Jameton's interchangeable use of the terms 'moral dilemma' and 'moral conflict' and the implication that he adopted a

commonsense notion of moral dilemmas, aligning dilemma with moral conflict. If one accepts Fourie's interpretation, this leads to the conclusion that moral distress cannot occur during experiences associated with conflict, dilemma or uncertainty. This conclusion conflicts with some of the empirical accounts of moral distress and is therefore problematic. One response may be that these empirical accounts are mistaken about what moral distress is because they have not met the necessary and sufficient conditions of judgement and constraint. Alternatively, one could accept those accounts and expand Jameton's narrow definition to accommodate them. This has been the approach of researchers who have suggested that moral distress needs to be decoupled from constraint and understood as a broader, more complex phenomenon (Hanna, 2004; Källemark et al., 2004; Fourie, 2015; Campbell et al., 2016).

Thirdly, the ambiguity surrounding the notion of moral integrity suggests that for now, this condition should not be incorporated into the definition. Attempts to use moral integrity to clarify moral distress only defer the problem because of the different conceptions of moral integrity. If, however, the empirical findings suggest otherwise, this condition can be incorporated into our understanding of moral distress.

Finally, although Jameton (1984) did not incorporate the psychological distress component into his definition of moral distress, since Wilkinson (1987/88) it has become a necessary condition of moral distress. Indeed, appealing to a commonsense understanding of the term 'moral distress', it seems obvious that any distress causally associated with a 'moral event', such as a moral dilemma

or moral uncertainty is, *ipso facto*, moral distress. Although commonsensical, this does not necessarily clarify anything, and the problem remains of defining what a ‘moral event’ is and of determining what the causal association between the ‘moral event’ and the distress looks like.

Due to the findings of other empirical studies and the theoretical problems associated with a narrow understanding of moral distress, the following definition of moral distress is proposed. This definition will then be revised as necessary in light of the empirical findings in chapter 5:

Moral distress is a combination of the

- (i) the experience of a moral event,
- (ii) the experience of ‘psychological distress’ and
- (iii) a direct causal relation between (i) and (ii)

Through this literature review, I have raised a number of key questions which, I argue, are left unanswered by the current literature. These questions will be used to inform the next phase of this project as I aim to have further ‘encounters with experience’ (Ives, 2008). In the next chapter, I will discuss the empirical methods that underpin empirical data collection and analysis, and how these cohere with the underlying methodology of feminist bioethics described in chapter 2.

CHAPTER 4: EMPIRICAL METHODS

4.1 Overview

In chapter 1, I outlined the aims and objectives of this thesis. The first aim is to develop a theoretically robust conceptualisation of moral distress, which is meaningful in the context of UK nursing; and the secondary aim is to develop recommendations for how moral distress ought to be conceptualised and responded to. To meet aim 1, the following objectives were identified:

- (i) To carry out a systematic literature review and formulate a plausible working definition of moral distress.
- (ii) Using face-to-face, semi-structured interviews, obtain an in-depth understanding of UK nurses' experiences of moral distress, what they perceive to be causes of moral distress, how they feel it affects them, and how they can be supported.

The first objective was completed in chapter 3 (literature review) and within this chapter, I will discuss the method that I used to gather the empirical data to meet objective 2. I will begin by introducing two philosophies of phenomenology – Husserl's and Heidegger's - and how their branches of phenomenology can be understood and used as qualitative research methodologies. I will discuss how phenomenology can cohere with feminist theory to form a feminist phenomenology, and why feminist interpretive phenomenology is suitable for this project.

4.2 Phenomenology as a Philosophy, Phenomenology as a Method

In this section, I will discuss phenomenology in the context of the philosophical tradition and its adaptation into a qualitative research methodology. It is worth noting, however, that some authors, notably Paley (2017) and Crotty (1997), dispute the links between phenomenology as a philosophy and phenomenology as a qualitative research methodology. Paley (2017) argues firstly, that it is not altogether clear to what extent the methods are actually derived from the philosophy and secondly, how phenomenology as a qualitative methodology is different to other qualitative methods, such as grounded theory or narrative enquiry. In this chapter, I will endeavor to respond to these criticism by highlighting the links between the philosophy and the research method. Then in section 4.4, I describe why phenomenology is the most suitable qualitative methodology for this project.

However, a detailed response to Paley's (2017) viewpoint is beyond the scope of this thesis because I cannot fully explain, in just a few pages, how Husserl and Heidegger's vast works can and should be read in order to inform the qualitative methodologies that have sprung from them. Rather, my argument is that there are fundamental ideas that can be found in both philosopher's work that seem to have directly influenced research methods used by qualitative researchers that are attentive to them, and this makes it coherent to state that the methodology is derived from the philosophy. In the next two sections, I will highlight these key ideas and discuss how they can be interpreted as influencing the methodologies within the literature.

4.2.1 Husserl's Phenomenology and Descriptive Phenomenology

Phenomenology was developed at a time when the concept of consciousness and its relation to the external world were being re-examined within philosophical circles (Cerbone, 2006). Phenomenology means primarily “description of the things presented in our experience and description of our experience of them” (Dostal, 1996, p.141). Phenomenology provided a new way of doing philosophy and a new way of thinking; for Husserl who is often credited as the founder of phenomenology it was a “science of consciousness” and for Heidegger it was an “approach to being” (Crowell, 2013, p.1). These differences in the underlying philosophy are translated into the research methods that developed from them. I will first describe Husserlian phenomenology which is often regarded as ‘descriptive phenomenology’. In the next section, I will discuss Heidegger’s phenomenology and why it is regarded as ontological, ‘interpretive’ or ‘hermeneutic’ phenomenology.⁷

In the ‘The Idea of Phenomenology’ and Husserl’s 1907 Göttingen lectures, Husserl introduces the ideas that are regarded as “radically Husserlian”: phenomenological reduction, ‘bracketing’ or epoché; ‘eidetic abstraction’; and

⁷ These categories are disputed by some writers, for example Dostal (1996), who argues that ontological concerns can also be about ‘essences’ and fundamental categories which Husserl also explores in his phenomenology. I will however be drawing upon an interpretation of Husserl’s phenomenology from Moran which largely supports this categorisation of Husserl’s work as descriptive.

‘pure phenomenon’ (Nakhnikian, 1964, p.13; Moran, 2000).⁸ I will discuss these three dominant ideas and the ways in which they have been translated into different research techniques that follow the Husserlian tradition.

Husserl (1964) begins the Göttingen lectures by stating that phenomenology “denotes a science, a system of scientific disciplines... and above all denotes a method and an attitude of mind, the specifically *philosophical attitude* of mind, the specifically *philosophical method*.” (<23> p.19). Husserl was influenced by Descartes who famously stated, ‘I think therefore I am’ (Cress, 1998) asserting that the only thing he could be certain of was the existence of his own mind. Husserl’s philosophical method of investigation begins therefore like Descartes, presuppositionless. Husserl only wanted to admit intuitions and experiences that he could be certain of and eliminate anything that may distract his consciousness, so he introduces the idea of ‘reduction’ (Moran, 2000). To begin one’s phenomenological inquiry, one must suspend or ‘bracket’ all beliefs that are not beyond dispute – for example if I see a chair, I need to suspend my belief in the chair. The ‘phenomenological reduction’ or epoché means “everything transcendent (that which is not given to me immanently) is to be assigned the index zero, i.e., its existence, its validity is not to be assumed as such, except at most as the phenomenon of a claim to validity” (Husserl, 1964, p.4 <6>).

Whilst Descartes wanted to understand how you could move from what ‘I’

⁸ Husserl seemed to use some of these terms interchangeably, for example throughout his works and the literature, the ‘phenomenological reduction’ is also called the ‘eidetic reduction’ and ‘transcendental reduction’ (Moran, 2000).

perceive to what really exists in the world, Husserl's phenomenology is regarded as epistemological and descriptive because he was concerned about how we come to know things, and he used descriptions of experience to reach understanding. Nakhnikian (1964) suggests that Husserl wanted to avoid the "paradox" (as Nakhnikian, 1964, p.15 names it) of Descartes' dualism. Descartes' questioning about how he could move from what he 'knows' in his mind to what exists outside of him, led him to conclude that whilst he could be certain about his mind - that he is a 'thinking thing' - he could not be certain about the external world, nor the existence of his body. Nakhnikian (1964) suggests that Husserl avoided this "problem about justifying our 'natural' belief in the independent reality of the world" because he was not concerned with existence or positing a transcendental world beyond experience, rather he was interested in their status as "phenomena for 'consciousness'" (p.16).

Husserl's reduction can be read in several ways. One reading implies that his method was solipsistic, that he was concerned primarily with introspection and one's own first-person perspective as a route to understanding and knowledge. By bracketing, he ignored the world and all questions regarding external reality and effectively endorsed skepticism about the external world (Zahavi providing an interpretation from Dreyfus (1991)). On this reading, I can see how Paley might doubt that Husserlian phenomenology can be translated into a qualitative research method that is concerned with others' lived experience.

However, Zahavi (2017) offers a reading that makes the connection between Husserl and descriptive phenomenology clearer. Zahavi (2017) argues that

Husserl was concerned with the objective world and our subjective experience of it and that his method did not involve turning away from the world and retreating into his own consciousness. The reduction and epoché was Husserl's method for putting aside one's 'natural attitude' (assumptions about the world). Husserl believed that in order to conduct a proper philosophical investigation, these assumptions needed to be set aside.

As Zahavi (2017) states,

“The reason why Husserl was so preoccupied with describing and analysing the fundamental features of consciousness was because he was convinced that a thorough philosophical understanding of the world that we experience and live in must include an investigation of subjectivity... His contention was rather that if we wish to understand how physical objects, mathematical models, chemical processes, social relations, cultural products can appear as they do and with the meaning they have, then we will also have to examine the subject to whom they appear.” (p.27)

Qualitative research techniques that follow a Husserlian approach also begin with this 'bracketing' exercise. The researcher is encouraged to set aside their own beliefs and preconceptions about the phenomenon under investigation and access the experience through another's experience of it (Giorgi, 1985). Meaning is built through shared structures of experiences. Critics of the Husserlian approach often argue that bracketing isn't possible, that one cannot begin their investigation presuppositionless. However, Zahavi (2017) argues that it is an ideal starting point that one can strive for. Once the phenomenological reduction has been conducted and all beliefs have been

suspended, if a singular experience is examined and perceived appropriately, then it can provide insight into the universal truth (Moran, 2000).

Following the reduction, Husserl turns to a careful description of the things presented to our consciousness, to the ‘things themselves’ within our ‘world of experience’, or ‘life-world’ to continue his investigation (Moran, 2000). The next step for the researcher therefore is to gain as thorough a description of the phenomenon as possible. The researcher conducts the interview, led by the participant and their perception of the experience, encouraging them to provide a rich, detailed and full description of their ‘life-world’. The researcher continues to ‘bracket’ their preconceived ideas and analyses the (usually transcribed) interview, paying close attention to the description of the phenomenon.

For Husserl, phenomenology is not a factual inquiry but an eidetic inquiry aimed at uncovering what is essential and reduction provides a way of suspending all belief to access essential structures of experience (Crowell, 2013). This “move from the individual intuition to the grasp of the universal is a move to grasp the essence; this is what Husserl terms *eidetic intuition*”, or eidetic reduction (Moran, 2000, p.134). This is not to be misread as a Platonic universal because Husserl (1964) stresses that this is not an *a-priori* investigative method but “proceeds by ‘seeing,’ clarifying, and determining meaning, and by distinguishing meaning” (p.46 <58>). It is not an abstractionist and universal account, but a process to discovering the essence of phenomena (Moran, 2000). It is through eidetic reduction that we are able to grasp the

perception of the chair through actual experience. Once the phenomenological reduction has been performed, Husserl argues that we can apprehend the “absolute datum”, the “pure phenomenon” of the world (Husserl, 1964, p.5 <7>). Giorgi (1985) translates this into the research methodology by suggesting that researchers must immerse themselves in the data. This is done by analysing the interview transcript line-by-line, finding commonalities between interviews and building common themes between them. These shared themes provide insight into the essence of the phenomenon and the characteristics deemed to be essential for understanding.

4.2.2 Heidegger’s Phenomenology and Interpretive Phenomenology

Heidegger was Husserl’s student and has been credited with transforming phenomenology into hermeneutic phenomenology because of his fundamental belief that the route to understanding the world was not as simple as Husserl had suggested (Moran, 2000). Zahavi (2017) highlights how Heideggerians did not see the necessity of the epoché and the reduction. Unlike Husserl, he believed that the appearance of self-evidence was a façade and throughout his work he discussed the notion of phenomena both revealing and concealing itself (Moran, 2000). One passage in ‘Being and Time’ reads:

“What is it that phenomenology is to ‘let us see’? What is it that must be called a ‘phenomenon’ in a distinctive sense? What is it that by its very essence is *necessarily* the theme whenever we exhibit something *explicitly*? Manifestly, it is something that proximally and for the most part does *not*

show itself at all: it is something that lies *hidden*, in contrast to that which proximally and for the most part does show itself; but at the same it is something that belongs to what thus shows itself, and it belongs to it so essentially as to constitute its ground” (Heidegger, 1962, II, p.59).

From this extract, we can see that Heidegger did not believe that the world simply reveals itself to us and in order to gain meaning, interpretation was required (van Manen et al., 2016).

“The phenomenology of Dasein is *hermeneutic* in the primordial signification of this word, where it designates this business of interpreting”
(Heidegger, 1962, II, p.62).

Heidegger originally entered the Jesuit seminary but had to leave due to ill-health and went on to study theology. It was during his early years studying theology that he encountered hermeneutics, as he considered the relations between scripture and theological thinking (Moran, 2000). As his work developed, he incorporated hermeneutics into his thinking regarding the “deeper ontological question” of time (Dostal, 1996, p.151) and Dasein, or ‘being-in-the-world’ (Heidegger, 1962). Heidegger believed that it was only through phenomenology that the question of being could be raised and explored, and since interpretation is essential for uncovering real meaning and “hermeneutics is the art of interpretation”, his phenomenology became an ontological, interpretive, hermeneutic phenomenology (Moran, 2000, p.197; van Manen and Adams, 2010)

According to Mulhall (2002), Heidegger believed that previous philosophical inquiry regarding 'being' had over-simplified different kinds of phenomena and so reduced the "richness of their differentiation" (p.6) Unlike Husserl, Heidegger did not believe that you could begin your exploration of 'being' presuppositionless and put aside one's previously conceived notions (Mulhall 2002). Indeed, Moran (2000) praises 'Being and Time' as "one of the strongest anti-Cartesian, anti-subjectivist, anti-dualist, and anti-intellectualist explorations of what it is to be human" (p.193). Heidegger disagreed with stripping away the world and all that we know to achieve understanding, believing instead that it was vital. As Hoy (1996) states: "Heidegger conceives of Dasein and world as forming a circle, and he thus extends the traditional hermeneutic circle between a text and its reading down to the most primordial level of human existence. Traditionally the paradigm for the hermeneutic circle is the reading of a text, where the parts cannot be interpreted without an understanding of the whole, but the whole cannot be grasped without an understanding of the parts" (p.172). In Heidegger, the hermeneutic circle is essential for achieving understanding as one must move between their 'historicality' (their background understanding and preconceived notions), their experience of being-in-the-world and their interpretation of being-in-the-world, to achieve understanding.

These differences between Husserl and Heidegger are reflected in the specific techniques that are required to conduct research following their traditions. Heidegger believed that if one 'brackets' out one's preconceived ideas in the way that Husserl suggested then paradoxically, they become further from

achieving a genuine experience of the phenomenon (Koch, 1996). Therefore, for researchers using a Heideggerian interpretive phenomenological methodology, the emphasis is on interpreting and understanding the data rather than only describing it; paying attention to the nature and meaning of the language being used to describe the experience (Robertson-Malt, 1999). This is because Heidegger began from the premise that humans are already embedded in a world of meaning and things are not first constituted in consciousness, thus to achieve understanding interpretation was required. Conversely, the descriptive phenomenological researcher must produce a much more descriptive account. In the next section I will discuss how phenomenology can be combined with feminist theory and I will describe the steps that I will follow to carry out for a feminist interpretive phenomenological approach.

4.3 Combining Phenomenology and Feminist Theory

Fisher (2000) suggests that the appearance of two fundamental incompatibilities create the perception that feminism and phenomenology are not compatible: that phenomenology is both essentialist and masculinist. In this section, I will suggest that these two incompatibilities can be overcome if one adopts a more sympathetic - or as Simms and Stawarska (2013) suggest, a more “progressive” - reading of phenomenology (p.6). In this section, I am going to argue that Heideggerian phenomenology is easier to defend against these charges than Husserlian. Additionally, because I do not want to ‘bracket’ my preconceived notions or existing theory regarding moral distress but instead use them to develop my definition, I will use a feminist interpretive phenomenological approach.

On an essentialist reading, phenomenology can be interpreted as seeking to abstract, objectivise and then universalise to access and understand the true essence of experience and as a consequence, experience is stripped of its uniqueness (Fisher, 2000). Since experience is stripped of its uniqueness, this creates the appearance of gender-neutrality, or worse male bias which contributes to the second perceived incompatibility between phenomenology and feminism, of masculinism (Fisher, 2000). Indeed Al-Saji (2010) suggests, “Husserlian phenomenology seems to uphold a disembodied structure of consciousness...[and] the phenomenological reduction claims to bracket not only the object-in-itself, but also, on the subjective side, the empirical ego – with all that this includes of concrete body, personal historicity, and, not mentioned by Husserl, gendered and racialized difference” (p.15) Here, Al-Saji (2010) critiques not only the disembodied consciousness that Husserl seems to describe, but also his method of phenomenological reduction. The argument being that the epoché requires an individual to bracket their unique understanding of themselves and their position in the world, thus disregarding their gender, race and social position. This is problematic for feminism which seeks to highlight how these factors affect one’s experiences in the world.

Al-Saji (2010) suggests that one possible response could be to argue that Husserl’s reduction just is not possible, or that it is incomplete, whilst accepting other parts of his phenomenological thesis. However, the reduction is central to Husserlian phenomenology and to reject this aspect would call into question other areas of his work (Zahavi, 2017). An alternative defense of Husserl’s

reduction is that he is simply providing a jumping off point from which one can begin their philosophical investigations, akin to Rawls's 'veil of ignorance' – once the reduction is complete, our post-bracketed understanding (our 'transcendental' understanding) is furnished with the concepts that belong to our pre-bracketed understanding (our 'natural attitude') (Heinämaa, 2017). According to Steinbock's (1995) reading of Husserl, a type of "generative phenomenology" can be found in his later writing in which, likely influenced by Heidegger, he tries to incorporate intersubjectivity and historicity into his phenomenological method. Heinämaa (2003), for example, highlights how Husserl critiqued Descartes' philosophical method as scientific and mathematical in nature (reductive) and suggests that philosophy can either be "declared scientific and modelled on mathematics and logic or it is claimed to diverge from the sciences and become poetry" (p.13). Comparing philosophy to poetry highlights how Husserl saw experience as rich and unique and he believed it was the philosophers task to turn from a description of particulars to create a unifying account of experience. Husserl's phenomenology is a "*pure descriptive theory of the essential nature of the immanent formations of Consciousness*" (Husserl, 1958, Ideas 2 §60, p.178). The process to discovery is through uncovering the essences of phenomena, but the aim is not to produce an abstractionist and universal account but to capture the richness of experience through description. Al-Saji (2010) notes, a more sympathetic reading of Husserl does allow for Husserlian phenomenology to be read in "productively feminist directions" (p.14) but a full defense of Husserl is not possible within this thesis.

A sympathetic reading of Heidegger is, however, more straightforward. In Heidegger, our unique 'historicality' enables us to interpret the particularities of immanent experiences which bring a unique perspective to our understanding of being in the world (Koch, 1996). It is harder therefore to charge Heidegger as essentialist because he values uniqueness, believing that it is crucial for interpretation and understanding. Heidegger's historical method of inquiry cannot be universalised and this has consequences for transferability which will be discussed in chapter 7 (Moran, 2000). Rather, shared and common elements can be highlighted and unified so that the subjective and collective experiences provide rich data with which to develop our knowledge of phenomena. This is more readily compatible with a feminist approach which views one's positioning in the world as vital for understanding. Importantly, I want to use my own experiences as a critical care nurse, my understanding of what it is like to work in this environment and to be challenged with difficult ethical problems to help me to understand and interpret the participants' lived experience. In the next section, I will discuss the ways I used my own experience to help me interpret the data whilst also producing trustworthy results.

Phenomenology and feminist theory both share a similar tension between capturing what is unique, subjective and individual and what is shared, necessary and essential to understanding phenomena (Fisher, 2000; van Manen and Adams, 2010). Both feminism and phenomenology struggle with the question of how we can marry the two into a unifying theory of phenomena. In feminism, identifying shared experiences has political implications as it is used as evidence of the oppression of women and marginalised groups within society.

In phenomenology, the problem is more philosophical as we try to build a unifying understanding of phenomena whilst also accounting for our unique position within the world – our historicity (Heidegger, 1962). This tension can be somewhat reconciled by carefully and thoughtfully recognising that it is present. The creation of unifying accounts ought to always contain the caveat that there are likely to be experiences that fall outside of the theory. Indeed, good qualitative researchers show an understanding that they are unlikely to capture the entire breadth of human experiences. Attempts to sample across age, gender, class and race will not ensure that all experiences are captured. Van Manen and Adams (2010) suggest that a phenomenological text thrives upon this tension:

“Without this tension, the qualitative research text tends to turn flat, shallow, boring, because it loses the power to break through the taken-for-granted dimensions of everyday life” (p.450)

Nonetheless, for my purposes, because this tension is shared by both phenomenology and feminism, it does not make them incompatible but rather an area that requires further attention. I will come back to this tension again in chapter 7.

The second perceived incompatibility between phenomenology and feminism is that phenomenology is masculinist. In this section, I am going to argue that whilst Husserl and Heidegger may not have provided female accounts of bodily lived experience, their rejection of the kind of mind-body dualism that can be

found in Descartes⁹ at least places their philosophical exploration within the realm of bodily lived experience, rather than upon accessing a transcendental realm. Fisher (2000) argues that their failure to explore female experience does not have to necessitate a male bias but rather an omission and framed as such, phenomenology can be interpreted as a basic framework to be applied to other areas of inquiry.

Indeed, prominent feminists have taken phenomenology to be a springboard with which they can examine women's issues, for example Beauvoir, Irigay and Young. Whilst Young (1990) remains critical of previous phenomenological philosophies (and Beauvoir), suggesting that their implicit gender neutrality implied male experience was the norm, Heinämaa (2003) argues that Husserl's "rigorous science' provided the conceptual framework for Beauvoir's feminist inquiries" in 'The Second Sex' (p.14). Heinämaa (2003) states that "Le deuxieme sex is not a thesis about women's socialization, but a phenomenological inquiry into the constitution of the meaning of sexual difference" (p.8). Beauvoir (2011) provides in-depth descriptions of embodied lived experience to provide insights into being in the world, the relationship of

⁹ The extent to which Husserl successfully rejected dualism is debated – see for example Dastur (1983), and despite Heidegger's rejection of dualism, whether he actually provided an account of the relationship between body and mind is debated – see for example Overgaard (2004) and Aho (2009).

men and women, and female subordination.¹⁰ Beauvoir problematises the assumption that sexual difference is irrelevant to descriptions of experience and she provides a phenomenological exploration of the meaning of sexual difference and the origin of hierarchy between men and women (Heinämaa, 2003). In ‘The Second Sex’, we can see how Beauvoir has adopted a phenomenological method of inquiry and description, and directed it towards feminist bodily experiences to make a distinctly feminist inquiry. It is by directing one’s inquiry to “the importance of discovering, unveiling or problematising hitherto taken for granted, hidden, unseen, forgotten or repressed aspects of the concrete everyday world” that phenomenology can take a feminist turn (Holm and Liinason, 2007, p.9). If we accept the perceived masculinist nature of phenomenology as a point from which to begin our inquiries into women’s experiences, then feminist theory and phenomenology can be viewed as compatible.

In chapter 2, I discussed how feminist bioethics critiqued ‘mainstream’ Western philosophy – in particular, for its failure to explore women’s experiences and its focus on abstraction and logic as a route to attain knowledge. Hutchings (2003) discusses how feminist philosophy also largely developed in response to the “explicit and implicit masculinism of the philosophical tradition” (p.2) and how feminist philosophy attempts to break down the hierarchical binaries that

¹⁰ It has been debated whether Beauvoir (2011) is distancing herself from phenomenology in *The Second Sex*. Although Heinämaa (2003) argues that *The Second Sex* is phenomenological in its aims and methods.

have been developed. Hutchings (2003) lists the more privileged binaries first- “mind/body; form/matter; reason/emotion; universal/particular; transcendent/immanent; ideal/real; truth/opinion; absolute/relative’ (p.9). Jagger (2001) and Hutchings (2003) both argue that women have traditionally been associated with the less privileged binaries of emotion, particularity and heteronomy, whilst men are associated with reason, universality and autonomy. However, through feminist phenomenology these binaries are blurred, as Fisher (2010) argues feminism and phenomenology both contribute vital elements to one another:

“Phenomenology can provide the style for an analysis which retrieves and retains the immediate, vibrant, tangible, and compelling lived experience, and enables our understanding of the phenomena and meanings of this lived experience and situation; while feminist thought and analysis can expand and deepen phenomenological investigation by recalling and insisting on the importance of the lived context, and the multiple aspects, particularities, and dynamics of the social and cultural world, of social and political being in the world, and the necessity of a phenomenological analysis and framing of these phenomena.”

(Fisher 2010, p.94)

To summarise, broadly speaking interpretive phenomenologists and feminist theorists share the basic understanding that individuals are uniquely positioned in the world - whether this is based on their preconceived understanding, sex, gender or race – this ‘historicality’ affects how they understand and experience

the world (Koch, 1996). This led Heidegger to reject the epoché and bracketing of one's preconceived notions, and researchers following the Heideggerian approach must begin with the understanding that the researcher is already embedded in a world of meaning and "inevitably brings certain background expectations and frames of meaning" into the act of understanding which cannot be bracketed (Koch, 1996, p. 176). Similarly, feminist research begins with the understanding that human experience is subjective, contingent and "woven with personal and cultural webs of signification" (Simms and Stawarska, 2013, p.12). Therefore, according to research methods that follow Heidegger's phenomenology, the researcher should use their preconceived notions, historicity and interpretation to guide data collection and data analysis. This makes Heideggerian phenomenology more compatible with feminist theory. In the next section, I return to some of Paley's (2017) criticisms and discuss how I will use feminist interpretive phenomenology in this project.

4.4 Feminist Interpretive Phenomenology as a Research Methodology

Phenomenology has become increasingly popular as a research method, especially within nursing. One suggested reason for this is because it appeals to the skills and interests of nurses as humanistic, interested in the holistic lives of their patients, with good communication at the core of their practice (Omery, 1983). Phenomenology as a research method encourages the researcher to allow the participant to lead the narrative and therefore values skills of active and empathetic listening which encourages the participant to open-up about their experiences. Phenomenology has therefore become a more gendered method as more female scholars have turned their attention to the lived experiences of

women and health issues that particularly affect women, such as in Lloyd et al. (2014) and Xiong et al. (2016). This work has encouraged greater reflection of women's bodily lived experience through a female lens.

This emphasis on experience has provided the justification for many researchers to adopt phenomenological methodologies. However, Paley (2017) is critical of this. He argues that this is “no justification at all” (Paley, 2017, loc 361¹¹) because other qualitative methods also aim to achieve the same thing. Paley (2017) argues that what sets phenomenology apart from other qualitative methods is ‘meaning attribution’ and he critiques prominent phenomenologists Giorgi and van Manen by arguing that they do not make it clear how they uncover meaning in their data sets¹². The reason for this, Paley (2017) argues, is that they are looking in the wrong place. He states, “All of them fail to comply with the axiom of resident meaning, even though they explicitly endorse it” (loc. 4035). Paley (2017) argues that van Manen goes beyond the text and uses relevant theory to find meaning in his data, despite his claims that only meaning can be found in the text. As this project is not strictly speaking a purely phenomenology-as-qualitative-research (PQR) project of which Paley's main criticism is towards, I am not wedded to PQR in quite the same way as van Manen. As this project is primarily empirical bioethics, I have already made it clear that I will be using theory to help me make sense of the empirical findings

¹¹ I am referencing a kindle edition of this book and therefore will be referring to location numbers rather than page numbers.

¹² I restrict myself to discussing Paley's criticisms of van Manen because I will be following his steps within this project.

and attribute meaning. Despite Paley's criticisms, I continue to use steps provided by van Manen for data analysis because he has provided specific guidance for researchers using an interpretive phenomenological approach (Earle, 2010). In the next sections, I will describe the specific steps that I took to collect the empirical data according to a feminist interpretive approach.

4.4.1 Data Collection

Paley (2017) argues that the researchers must be explicit regarding what they mean by phenomenon. He critiques other studies for being far too vague, for example one study stated they were exploring "recovery from breast cancer-related breast surgery" (loc. 4104). Paley (2017) argues that the failure to identify a specific phenomenon leads to studies that add very little to the literature because they fail to answer a specific research question. In this case, I have been specific regarding the phenomenon under-study (moral distress) and I have posited a list of questions unanswered by previous research that are used to inform data collection and analysis. Related to this, Paley (2017) also suggests that researchers fail to uncover significant findings because they are fearful of asking specific questions as they try to avoid imposing their agenda on participants. In this project, I tried to balance exploratory, open-ended questions with a more Socratic and challenging style of questioning. Data were collected using semi-structured interviews during which participants were encouraged to take me on their narrative journey (Koch, 1996). However, because the aim in empirical bioethics is to co-construct knowledge by being critically normative (Dunn et al., 2012) when participants were inconsistent

with their responses, I gently challenged them to try and gain clarity.¹³ Again, the combination of both PQR and empirical bioethics enables me to overcome some of Paley's criticisms of PQR.

Participants knew that the study was about moral distress as this was necessary to provide informed consent to participate in the research project, but importantly the concept was not pre-defined. The interviews remained open and non-directive so that the participant could lead the interview but I did use an interview guide to help with broad question and probes (Appendix 8). Whilst I kept my questions broad at the beginning of the interviews, I tended to ask more specific questions as the interviews went on. These questions were prompted by the participants experiences and by the questions left unanswered from chapter 3. For example, I began by asking participants to describe their experiences of ethical challenges, how and why these events had occurred and how they made them feel, and then towards the end I asked them to describe what they thought moral distress was. These responses were very useful for evaluative and summative purposes as I could weigh up the experiences they had described along with their articulated understanding of the term. I could then compare these more summative statements to the findings in the literature and previous definitions of moral distress. Participants were also asked about how they had managed their experiences and which of their coping mechanisms or existing support systems had been helpful, and any possible ways they could be supported in the future. Responses to these questions helped to inform

¹³ I discuss this style of questioning again in section 5.3.2.

recommendations regarding how we ought to respond to moral distress.

The aim was to seek as complete a description as possible, and to thoroughly probe responses. It was anticipated that interviews would last from 45-90 minutes but most of the interviews were around 120-150 minutes. Participants became part of the research process as soon as they had participated in the interview. This made the offer of withdrawal at any time extremely problematic because their contribution couldn't be forgotten and their narratives uninterpreted. However, it is important that participants are provided with the option to withdraw and they could withdraw up to four weeks after their contribution without giving a reason. After that point, participants were advised that their data would have been interpreted and so could not be withdrawn. Participants were advised that should they want to withdraw after the four-week window then their anonymised verbatim quotations would not be used within the thesis or any published reports. Fortunately, no participants requested to withdraw. In fact, one participant sent a follow up email with additional thoughts following the interview which was also considered along with the rest of their data, with a note that it had been added later.

In the first of four excerpts from my reflexive research diary, I reflect upon the interview process and balancing respect for participants' emotional experiences with the need to probe their responses.

Box 2: Reflexivity (1)

Prior to beginning the interviews, I thought that participants might find the process cathartic because they would be provided with the space to freely discuss their ethical experiences. This did indeed seem to be the case and many participants expressed the fact that they are very rarely able to speak about their experiences in such an open way. Participants shared experiences that had affected them deeply and many of them became upset and cried during the interviews. Participants were given the space and opportunity to pause or stop but they all chose to continue. I got the sense that they wanted to discuss their experiences, to share them and almost unburden themselves. Some of the participants seemed to come to the interviews with their story ready. They had a specific experience that they seemed to have planned to discuss.

I originally thought the interviews would be about an hour long but most of them were two hours if not more. I think the fact that I could understand their experiences without further explanation was helpful for the flow of the interview. Participants didn't have to stop and explain the circumstances or medical terminology. I find that I prefer to discuss my difficult clinical shifts with my nursing friends rather than with my friends or family because they just don't 'get it'. When I try to explain why a particular incident was shocking, I have to keep stopping and explaining the details and instead of feeling like I've got something off my chest, I feel frustrated that I can't just rant. I felt like this was how the participants felt too.

There were times that I struggled to juggle my commitments as a researcher, clinician and individual. I felt guilty that many of the participants were becoming upset recalling their experiences and was cautious not to probe too deeply where experiences were clearly distressing. I was mindful to allow them time to stop, move on or continue, and I stressed that there were psychological support services available at their place of work (noted on the participant information sheet). As a clinician, there were times that my own experiences converged with the participants, for example one participant articulated the deep distrust he felt towards some surgeons, wondering whether they sometimes continued aggressive treatments because of a concern for their mortality figures rather than for the patient. I had also experienced something very similar and so I was cautious not to dwell on this experience just because it was relatable but to instead allow the participant to spend as much time on the experience as they needed. As an individual, I hadn't considered the support mechanisms I might need for myself listening to these frequently sad experiences. I found my supervisory team and a colleague invaluable in this respect as I was able to decompress and think about my own emotions with them (whilst of course maintaining confidentiality).

4.4.2 Sampling

Purposive sampling was used to recruit nurses from critical care settings. Patients are seriously ill when in critical care and require increasing support and interventions to keep them alive. None of these interventions are without pain for the patient or the risk of serious complication, therefore difficult ethical decisions regarding patient care need to be made in ICU, making this subset of nurses a potentially rich source of information. Many previous studies exploring moral distress in other countries have been carried out in this setting and have found ‘moral distress’ to be present, therefore allowing for comparisons to be made (Elpern et al., 2005; Gutierrez, 2005; Hamric and Blackhall, 2007; Atashzadeh Shorideh et al., 2012). Table 10 shows the inclusion/exclusion criteria for participants with slight variability between sites due to a specific request from site 2.

Table 10: Inclusion/Exclusion Criteria for Participants

Inclusion Criteria	Exclusion Criteria
<ol style="list-style-type: none">1) They are a registered nurse with the Nursing and Midwifery Council.2) They are currently working in an adult critical care area (intensive care or high dependency setting).3) They have worked on the unit for more than 6 months (site 2 only- due to local request)4) English- speaking.	<ol style="list-style-type: none">1) They are not a registered nurse with the Nursing and Midwifery Council.2) They are not currently working in an adult critical care area (intensive care or high dependency setting).3) If they have not worked on the unit for more than 6 months (site 2 only- due to local request)4) They are not English-speaking.

4.4.3 Recruitment

It was estimated that a maximum of 30 participants would be recruited because this is a manageable and an achievable number given the time frame. Participants were recruited from two large NHS Trusts¹⁴, both of which have busy trauma centres and critical care units. Representatives from both Trusts

¹⁴ NHS hospitals are grouped into overarching organisations called NHS Trusts which oversee the management of each hospital.

confirmed, subject to research governance and ethical approval that they would support the use of their organisations as recruitment sites.

The recruitment processes differed slightly between the two sites due to local preferences. At site 1, following ethical approval, and relevant R&D permissions, unit managers were approached via email for consent to recruit on their units (Appendix 9) and were offered the opportunity to discuss the research in person. I met with the unit managers and answered questions they had about the research. The unit managers were then asked to forward the information sheet for potential participants (Appendix 10 and 11, Trust specific) to nurses on their unit. After two weeks, the unit manager was then asked to circulate reminder letters of invitation to serve as a reminder of the project.

At site 2, the Assistant Director of Nursing and two Practice Development Nurses circulated the information sheet for potential participants to eligible nurses (Appendix 11, Trust specific). Site 2 requested that nurses had worked in critical care for a minimum of 6 months in order to participate¹⁵. Nurses who were interested in participating filled in a slip at the bottom of the recruitment letter and placed this in a secure, centralised box. I then contacted only those who had provided their contact details, answered questions and allowed the potential participants time to decide whether to participate. Two participants

¹⁵ This was due to the preferences of a gatekeeper at this site. It is difficult to determine whether this had any impact as none of the participants that volunteered from site 1 had less than 6 months' experience either.

provided their contact details, were contacted but did not respond and so were not recruited into the study.

Permission was sought from unit managers at both sites to display recruitment posters advertising the project in staff areas and to speak to staff regarding the project on training days. Site 1 did not have any training days running but site 2 had three at which I was able to provide a short presentation of the project. Several of the participants informed me that they had chosen to take part because of these presentations. It was predicted that due to the busy nature of the clinical environment, participants would be required to participate in interviews outside of clinical duty hours and so they were thanked with a £20 Amazon voucher for contributing their time. Site 2 requested that this was not advertised on the recruitment poster but it was advertised on Site 1 recruitment posters. The Trust representatives were approached for permission to circulate an advertisement on the Trust intranet and departmental newsletters but unfortunately, I did not receive a response regarding whether this would be permissible and so this wasn't distributed.

All recruitment materials contained my email address and interested participants could confidentially contact me directly. During initial contact, I confirmed eligibility, answered any questions and checked the participant had read the information sheet. I was careful to allow potential participants to have the time to read the information and consider whether they wanted to participate before sending a follow up email. Once a participant confirmed they wanted to

participate, I arranged a time and place to meet and asked for their phone number in case I needed to contact them urgently. I gave participants the option of either meeting in a booked room on site 1 or site 2 (away from the clinical area to maintain confidentiality) or I offered to travel to their house. Most of the participants preferred the second option and this was covered under the University of Birmingham's/ University of Bristol's lone worker policy. Appendix 12 outlines the plans put in place to contact the supervisory team before and after interviews.

Figure 4: Recruitment Flow Chart for Site 1

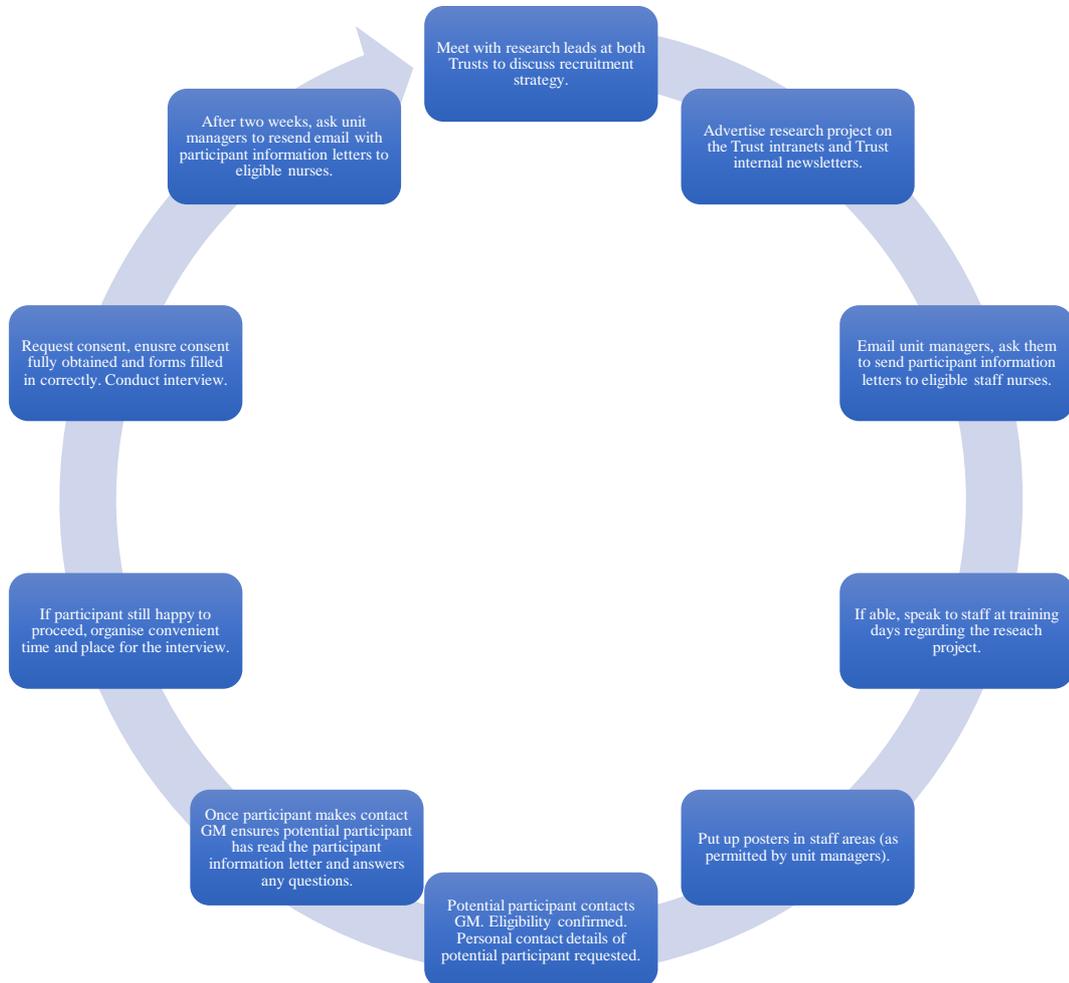
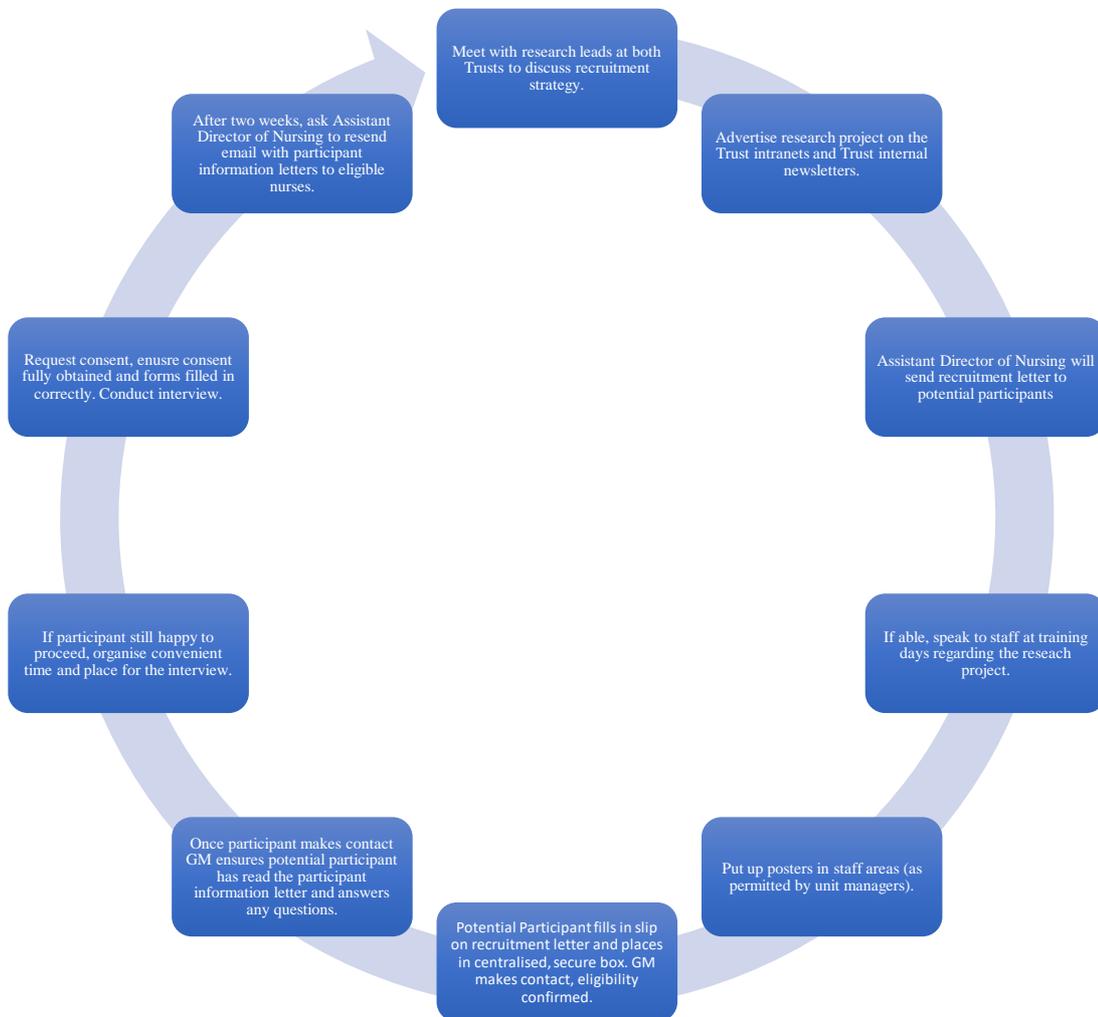


Figure 5: Recruitment Flow Chart for Site 2



4.4.4 Data Analysis

The aim of the researcher in an interpretive phenomenological study is to immerse oneself in the ‘hermeneutic circle’, which means moving between the singular experiences of each participant to the jointly shared experiences of them all and analysing the rich data (Koch, 1996). Robertson-Malt (1999) suggests that traditional philosophical hermeneutic phenomenology disclaims the existence of method, but that the pragmatics of research require there to be a recognisable approach. Indeed, the subjectivity of human experience that is central to phenomenology is at tension with the objectivity required to create a rigorous, replicable study. So, although van Manen (1990) believes the analysis of a text is an art, he recognises the requirement for a set of steps and recommendations in order to develop a principled inquiry, one that “neither simply rejects or ignores tradition, nor slavishly follows or kneels in front of it” (p.30). Indeed, having a set of steps to follow helps to make the data analysis process more manageable.

Data analysis is another point at which Paley (2017) criticises PQR, arguing that data analysis requires a specific theoretical perspective. Paley (2017) objects to van Manen’s belief that theory can only be found within the data. Paley (2017) does not see theory as either inductive or deductive, he sees it as crucial to each step, influencing all our interpretations of meaning. The interpretive nature of this project means that I used my own experiences, my feminist commitments (paying close attention to power, voice and relationships), feminist philosophy and knowledge of previous conceptions of moral distress to guide data collection and subsequent analysis. To enhance trustworthiness, I carefully

balanced the integrity of the data with my own experiences in order to interpret participants' narratives.

Van Manen (1990) suggests a dynamic interplay of six activities for interpretive phenomenology and these guided the data analysis process:

- 1) Turning to the nature of lived experience
- 2) Investigating experience as we live it rather than as we conceptualise it
- 3) Reflecting on the essential themes which characterise the phenomenon
- 4) Describing the phenomenon through the art of writing and rewriting
- 5) Maintaining a strong and orientated relation to the phenomenon
- 6) Balancing the research context by considering parts and whole

I completed the first two activities by immersing myself in the participant's narratives, conducting the interviews, making field notes, probing their accounts and reflecting upon the interviews. These two activities fed into the third, in which the key experiential structures that made up each experience were hypothesised. I came away from the interviews with an initial sense of some possible themes. These initial thoughts and reflections were recorded in my reflexive research diary which acted like an audit trail of data collection and analysis; making these steps transparent increases the trustworthiness of the project (Rolfe, 2004) I began by creating individual narratives for each participant to capture the key elements within their moral distress experiences. Then once the interviews were transcribed, analysis and coding of the text in NVivo began and I found I could completely immerse myself in the data.

Van Manen (1990) suggests three approaches towards uncovering or isolating themes within the data:

- (i) *The wholistic or sententious approach* in which the whole text is read and the fundamental meaning of the text as a whole is captured.
- (ii) *The selective or highlighting approach* in which the data is read several times and the statements or phrases that are particularly revealing about the phenomenon will be highlighted.
- (iii) *The detailed reading or line-by-line approach* in which the text is read in detail and each sentence examined in terms of what it might reveal about the phenomenon.

I began by reading the entire transcript again to remember the interview, the participant and their body language. I then re-read the transcript and highlighted words, sentences and sections as nodes in NVivo. Although theoretically I doubt whether data saturation is achievable, by interview 16 I found that I was no longer creating many new nodes, and those nodes that were created seemed to be particular to the individual and did not form large themes. Frequency of themes did play a part in this process, as codes were built if participants mentioned and repeated the same issues. However, only those deemed to be vital to the concept became essential themes. Paley (2017) argues that it needs to be clear how 'essential themes' are selected and decided upon. I have endeavoured to maintain transparency throughout the project to allow the reader to follow my interpretations and to make clear how the themes come through in

data analysis. In Appendix 18, I provide an example of theme development including coding in NViVO.

After coding in NVivo, I went back to the initial narratives that I had started immediately after the interview and added to them. As van Manen (1990) suggests in activity four, I added to the narratives and wrote a story that captured the participants' experiences. A sample narrative can be found in Appendix 17. Using the coding in NVivo and the notes I had originally made, I listed what seemed to be the key themes for each participant. I highlighted what appeared to be unique to individual experience and then as I moved forwards and backwards between the narratives, I compared the individual experiences to create shared experiences and this helped me to build common themes. As van Manen and Adams (2010) state, a phenomenological text thrives on an irrevocable tension between what is unique and what is shared. As I conducted the interviews and began participants' narratives, I compared these with the previous narratives. This meant that as I carried out data collection, I had a background awareness of the previous participants accounts which I could then compare to the present participants' narrative. As I identified the commonalities, I constructed sub-themes which then through shared experiences, became larger themes and eventually the whole, unifying theory and definition of moral distress. From the key themes, I then wrote the first draft of my empirical findings chapter. I re-wrote this chapter three times before realising that my focus was, erroneously, on the issues that surround moral distress, rather than on the concept itself.

Considering van Manen's (1990) activities five and six, I then went back to the data, the key themes and created a mind map illustrative of the concept of moral distress. This mind map was re-worked several times and discussed with my supervisors, and eventually became a model. In the model, I position moral distress in its constituent parts back into the world and suggest the way moral distress relates to other factors and concepts. The model was presented at two conferences before the final version was developed. Paley (2017) calls this a 'how-possibly' model and argues that they can be useful for moving from a description or interpretation of a phenomenon to an explanation of it. Indeed, model development was an invaluable process as discussing the model with individuals that had distance from the project helped me to identify weaknesses that required further development. The moral distress model and definition were then related back to the previously identified common definitions of moral distress for comparison. The final steps allowed the data to be re-contextualised within the broader narrative of moral distress in order to understand how moral distress should be defined within the UK context.

Paley (2017) suggests that some of his criticisms and recommended amendments are the antithesis of PQR. However, his criticisms are targeted mainly at those projects that are formulaic and stick to perceived rigidly prescribed rules of phenomenology. However, I do not regard interpretive phenomenology in this way and provided each step is justified, coherent and transparent then trustworthiness can be maintained. Even van Manen (1997)

argues, there is no one correct or superior method that will lead to the ‘uncontested truth’, for there is no one truth; rather, the aim of the method is to facilitate the interpretation of human experience. Van Manen (1999) intersects the ‘pragmatic’ and ‘methods-driven’ North American research methods, and the West European or continental traditions that leave the methodological procedures more implicit and sets out a methodological structure for an interpretive approach whilst also maintaining that lived experience is always more complex than an explication of that meaning can reveal (van Manen, 1990). Van Manen (1990) states that, “The phenomenological reduction teaches us that complete reduction is impossible, that full or final descriptions are unattainable” (p.18). Capturing the richness of the experiences described in the data in one neat definition of moral distress proved to be untenable. Therefore, whilst the definition of moral distress captures the key elements, it remains quite broad and construction of the moral distress model enabled the richness and complexity of the data to be captured. Importantly this can be built upon with further empirical research.

4.4.5 Ethical Considerations

(i) Research Approval

Approval for the project was first obtained from the University of Birmingham, reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee on 1st March 2016 (project reference: ERN_15-1168S). The University of Birmingham also provided sponsorship for the project on the condition of approval from the Health Research Authority (HRA). The HRA

approved the project (IRAS reference: 197577) on the 30th June 2016 and recruitment began at the start of August 2016. The project was also added to the National Institute of Health Research (NIHR) portfolio on the 9th September 2016. As I transferred to the University of Bristol in February 2017, a substantial amendment for a change of sponsor was submitted to the HRA (completed on 30th May 2017). These ethical approval documents can be found in Appendix 13.

(ii) Consent

Consent was requested before the interviews began. Participants were given the opportunity to ask questions and to confirm they had read and understood the participant information sheet before initialing and signing the consent form. Consent was requested for permission to audio record the interviews, for verbatim transcription and use of direct, anonymised quotations for use in the PhD dissertation and in subsequent publications (Appendix 14 and 15).

Participants were reassured that their identity would remain confidential and all data would be anonymised. Participants were assigned a numerical and alphabetic identifier, which was used to create a key between participants and anonymised data so that a participant's contribution could be withdrawn if requested. Participants were advised that they could withdraw up until four weeks after their interview without giving a reason. After four weeks, their data would have already been interpreted and so although the participant could withdraw, it was not possible to withdraw their anonymised data and instead

they were offered the option that verbatim quotations would not be used. None of the participants requested to withdraw. Once the interviews were transcribed, the original recording was deleted.

(iii) Data Storage and Confidentiality

All electronic data were stored as a master copy file (research protocol, transcriptions of interviews, participant's names and contact details) and on an NHS level encrypted USB stick that was locked in a filing cabinet in a secure university building. The data will be stored for 10 years following the project's planned completion in September 2018, in line with University of Birmingham policy.

Hard copies of the data were stored separately to the USB containing the electronic data in a locked draw in a secure university building. All data, except for the consent forms were anonymised. The consent forms, by their nature cannot be anonymised, and were stored in a locked filing cabinet in my office in a secure university building, separately from the anonymised transcripts. Following completion of the research fellowship and no later than 6 months after publication of the research, all data will be securely archived.

The interviews were audio recorded and the data sent to a third-party company for transcription. The transcription company (The Transcription Company UK) has a secure system in place to handle the data (256 bit SSL encryption) and signed a confidentiality agreement. The audio recordings were securely stored on an NHS level encrypted USB and deleted once transcribed. The transcripts

were labelled with a numerical identifier so that they could be withdrawn if requested and a key created to the pseudonym used in the later narratives. The anonymisation key was stored separately to the anonymised transcripts.

(iv) Safety

Due to the sensitive nature of the discussion, some participants felt emotionally distressed and upset sharing their experiences. Potential participants were informed of this risk prior to consenting. They were reassured that both data collection sites have 24-hour confidential counselling available and as employees they have free access to this. Participants were also advised that they could escalate any concerns to the project supervisory team if they felt the research process had harmed them in any way, and contact details were provided on the participant information letter.

There was a small risk that a participant could disclose professional misconduct. This risk was highlighted on the participant information sheet to inform participants that confidentiality could not be assured in those cases. According to the Nursing and Midwifery Council's (NMC, 2015) code of conduct, nurses have a responsibility to act if they believe themselves, a colleague or anyone else may be putting a patient at risk. If, through the course of an interview, it came to light that a nurse had put a patient at risk it would then be in the public's interest to break confidentiality in such cases. If this were to occur, I would discuss the potential case with the project supervisors and if necessary inform current employers and the NMC. The participant would also be informed that

confidentiality would have to be broken. No issues related to professional conduct arose during the course of the research process.

4.5 Conclusion

As Bradbury-Jones et al. (2009) argue, it is important that researchers understand the philosophical differences that form the foundations of different phenomenological research methodologies in order to determine whether their approach is suitable for their project. I have discussed two different phenomenological approaches that originate from Husserl and Heidegger, and the ways that Heidegger's phenomenology can be combined with feminist theory to form a feminist interpretive phenomenology which provides the tools required for data collection and analysis. In the next chapter I present the key themes that emerged from the findings and in chapter 6, I present themes that emerged as 'compounding factors'. These factors either mitigated or exacerbated participants experiences of moral distress. Then in chapter 7, I systematically challenge the account of moral distress that I have developed and I present the final moral distress model.

CHAPTER 5: EMPIRICAL FINDINGS: Moral Distress

5.1 Overview

The objective of this empirical bioethics project was to identify a plausible working definition of moral distress that could be refined in light of empirical findings. In this chapter, I present the empirical findings from interviews with critical care nurses about their experiences of moral distress which I use to inform the working definition of moral distress. At the end of chapter 3, I suggested the following working definition:

Moral distress is the combination of:

- (i) the experience of a moral event,
- (ii) the experience of ‘psychological distress’
and
- (iii) a direct causal relation between (i) and (ii)

This working definition captures the suggested necessary/sufficient conditions required for moral distress to occur and is derived from the literature. However, because this definition is broad, it also raises three important questions:

1. What kind of ‘moral event’?
2. How should we understand ‘psychological distress’?
3. What sort of causal relationship is required between (i) and (ii) to create moral distress?

The empirical findings shed light on these three important questions and are presented in the following sections:

- (i) psychological distress
- (ii) moral event
- (iii) causal relationship

As discussed in the previous chapter, the empirical data were collected following a feminist interpretive phenomenological approach. The focus of this chapter is to present my interpretation of the participants' experiences which are supported with verbatim quotations. Due to the uniqueness of individual experience, there are experiences that fall outside of the general themes and I will highlight these. Some of these are used for deviant case analysis and discussed in chapter 7 in order to challenge my proposed definition.

The empirical data are interwoven and punctuated with developing arguments and key pieces of theory and literature. This differs to the way results and interpretation of results are usually presented in qualitative research but is similar to the presentation of results in other empirical bioethics projects (for example, Jenkins et al., 2017). This variation is accepted within empirical bioethics because it is recognised that the presentation of results may need to vary according to the research question and aims (Ives et al., 2018). This style of presentation is also compatible with hermeneutic phenomenology as I use the empirical data and relevant theory to develop my interpretation of the participants' experiences. This iterative process between data analysis,

interpretation and theory can only really be articulated with this style of presentation. I suggest the difficulty of separating the empirical findings and ethical theory at this point is also representative of the deep entanglement between ‘empirical facts’ and ‘ethical values’ (Putnam, 2002), which is central to the methodology of reflexive balancing.

Table 11 provides the demographic information of participants. In total, 21 critical care nurses took part, with varying levels of experience and different educational backgrounds. Experience level isn’t always determined by banding and therefore I have listed years qualified and the band of each participant. Banding is determined by NHS Employers Agenda for Change¹⁶ and those band 6 or above are considered senior nurses. Generally, in critical care, band 5 nurses are assigned either one level 3 patient, or two level 2 (high-dependency) patients and because the majority of their time is spent at the patient bed-space providing continuous monitoring and care, they are often considered the ‘bedside’ nurse. Band 6 nurses are either assigned a patient similarly to a band 5 or they are assigned the role of ‘runner’ or ‘floater’ and it is their responsibility to assist and support junior nurses and ensure patients are cared for during staff breaks. In some Trusts, experienced band 6 nurses also lead the shift in which they assign patients, support bedside nurses, liaise with the medical team and coordinate admissions and discharges. The role of shift leader is more regularly the role of a band 7 nurse, and it is rare that a band 7 nurse would care for a

¹⁶ This is a not-for-profit organisation that sets the national pay system for nurses and allied healthcare professionals working in the NHS in the UK.

patient at the bedside. Band 8 nurses are often the matron or ward manager of the area and generally spend very little time in the clinical area.

Table 11: Demographic Information of Participants

Age Range	Number of Participants
25-34 years old	17
35-44	2
45-54	2
Gender	
Female	18
Male	3
Hours of Employment	
Full-time	18
Part-time	3
Primary Clinical Area	
General/Trauma ITU	15
Specialist ITU	6
Banding level	
Band 5 (junior)	12
Band 6 (senior)	6
Band 7 (senior)	2
Band 8 (senior)	1
Years in Current Role	Years Registered as a Nurse
<1 3	< 1 0
1-3 10	1-3 3
3-5 6	3-5 3
5-10 1	5-10 12
10-20 1	10-20 1
20 + 0	20 + 2
Highest Qualification	
BSc Adult Nursing/ Nursing	11
BSc Critical Care	1
Diploma Adult Nursing/Nursing	5
Postgraduate Diploma Adult Nursing	3
Other	1

5.2 Section (i) Psychological Distress

Perhaps one reason defining moral distress has been so problematic is because the word ‘distress’ conjures up not one singular emotion but several different emotions. Whilst I could list all of the possible associated emotions, I agree with Paley (reported in Morley, 2016) that emphasising the breadth of emotions isn’t necessarily helpful for clarifying a concept but, rather, that highlighting predominant emotions can bring clarity. In this section, I present the prevalent emotions that emerged from the participants’ narratives.

To gain insight into the emotions associated with moral distress, not only did I make notes and observe participants’ emotional responses during interviews, but I also asked participants to describe how each experience made them feel. In addition to my subjective interpretation, this enabled participants to clarify their emotional responses. As it can be difficult to capture emotion in written text, I have also selected some quotations in which participants are responding directly to this question to provide another layer of credibility. The aim is to enhance the credibility and trustworthiness of the data so that the reader can follow my line of interpretation.

To note, all names within this chapter are pseudonyms and I have removed “ers” and “ums” from quotations.

5.2.1 Anger

Anger and outrage were dominant emotions expressed by participants through verbal language, body language, physical expressions, facial expressions, and

as a direct response to questions about how experiences made them feel. Holly's narrative in particular was littered with expletives as she described her experiences. In the following quotation, Holly describes the moment a patient suffered a cardiac arrest and died after receiving what Holly perceived to be as futile and aggressive care. Holly seems to describe feeling a sense of injustice because the patient was receiving futile care and feeling obligated to attempt resuscitation without adequate support (working only with a locum registrar and struggling to contact the charge nurse) despite her belief the patient had no chance of survival.

"...they all fuck off and it's just me and the locum reg [a senior doctor who is temporary] who I knew was lovely and I'm like her blood pressure's just fucking going so cranking up the norad [continuous intravenous medication to support blood pressure], making tits difference, I'm like ringing the nurse in charge, he's like, erm, he's like oh, it's just your transducers like it's not just my fucking transducers, brother [transducers must be at a certain level to accurately measure blood pressure]. So then my other colleague who is solid, I say 'Richard, I need you in here'. I knew she was going to arrest. This poor doctor was trying to get other access in where her Vascath [intravenous access through which emergency medicine can be given] was beeping and alarming, the family were probably in some kinda happy oblivion because she'd been nearly dead so many fucking times, why would they think today was gonna be the day; they probably wouldn't think that. So, she did, she arrested and they put paddles [to provide shocks during a cardiac arrest] on and she, her skin was sliding around her body like plate tectonics and there was blood all through the bed.... Mum and dad weren't in there when...I don't think they got to spend time with her alive but I was heartbroken for her, for us [crying] for the fact that that situation should've never been allowed to happen. This was over two years ago and you can see the effect it's had on me. So, when my shift ended I, I was just like shit, I have to get a taxi home, I was just like shell-shocked, people are like are you alright, I was just like, no. I had like four days off as part of my rota after that. I helped, I stayed late to help lay her out 'cos that was sort of somehow sort of helped. The family were cool but obviously not. That was just the most brutal thing to have to experience." (Holly)

Many participants' narratives were centered around patients they believed were receiving 'futile' care, and therefore I use this word frequently throughout this chapter. However, I am aware that the term is subjective and difficult to define. Judgements regarding futility are often either based on quantitative reasoning using empirical/ numerical observation, or 'qualitative' reasoning that suggests the benefit to the patient is too low to outweigh continuing treatment (Demarco and Jones, 2017). Most of the participants seemed to be drawing on qualitative reasoning when articulating these judgements and seemed to believe that when the patient's chance of recovery was low or didn't outweigh the burden of their treatment, treatment was futile.

In a similar vein to Holly, Amelia also seemed angry when discussing cases of perceived futile care. In the quotation that follows she describes these situations like a *"nightmare"* and a *"horror film"*, akin to being in a *"weird dystopian"* world where patients are tortured instead of cared for.

"Jesus Christ", this just feel like a nightmare, like a horror film, like a weird dystopian thing...like we keep them alive even though they are dead! Why!? And it's like decisions aren't being made fast enough and they are not being made like in time, so the ward round will come around at 4pm and you're like, well the family have already been in, they've gone home now so you can't have the discussion you wanted to have with them. So, what's going to happen now...what's the plan? "Oh well we are going to wait for haematology to come in tomorrow...." And you're like oh great, another day of this. And it just feels cruel and it feels like its torture for this person." (Amelia)

Holly and Amelia both described feeling obligated to continue providing what they perceived to be futile care and described feeling constrained¹⁷ and powerless to change the situation, creating a sense of injustice for themselves (as powerless) and for their patients (receiving futile care). Delays in decision-making added an additional constraint by extending perceived futile care. Anger seemed to culminate from this combination of constraint, powerlessness and injustice and seemed to be more closely associated with participants feeling they knew the right thing to do but unable to carry it out. Interestingly, neither Holly nor Amelia discussed sharing their moral viewpoints with the rest of the team and so avoided engaging in moral conflict. These circumstances I label as ‘moral tension’; participants seemed aware of the moral issues and had a feeling about the right thing to do but did not engage in conflict with others. I will discuss this further in section ii.

The association of anger with injustice and moral wrongdoing is also suggested by Molewijk et al. (2011). In a paper exploring the utility of emotions within moral case deliberation, Molewijk et al. (2011) found that anger was often associated with judgements about fairness, justice and respect. This is also consistent with the work of moral psychologist Haidt (2003) who suggests that anger is a moral emotion often associated with goal blockage, frustration,

¹⁷ Participants seemed to describe a constraint as something which prevented them to act, and could be perceived or internal (such as feeling powerless or lacking confidence to act) and/or external constraints (such as the requirement to carry out medics’ decisions). It wasn’t always clear whether a constraint was real/perceived, internal/external. I will discuss constraints in more details in section (ii).

betrayal and injustice. Similarly, participants in this study described feeling angry when they thought they knew the right thing but were constrained (goal blockage) and consequently felt implicated in committing a moral wrong because of their reduced agency (injustice), thus mirroring Molewijk et al. (2011) and Haidt's work.

The source of moral wrong seemed to be variable and ranged from perceived futile care to lack of adequate staffing, which could then be worsened by additional factors such as poor communication or delays in decision-making. These additional compounding factors will be discussed in the next chapter. In Holly and Amelia's cases, the source of moral wrong seemed to stem from their expressed belief that patients were receiving overly aggressive care and that life-sustaining treatments should be withdrawn but neither of them had the power or authority to make this decision. However, there are other actions they could have taken. Perhaps, if they felt more confident and empowered, they could have initiated a conversation with the family about treatment decisions or requested a medic speak with the family. However, this option may not have felt possible if they lacked confidence (internal constraint), or if this was not supported within the unit's culture. This second option may have constituted an additional external constraint because they may have felt unable to persuade a medic to initiate this conversation. Some participants expressed the belief that it was not their place to break bad news to families and the topic of treatment decisions may have fallen within this. An additional constraint that was not acknowledged by either participant was professional guidance. According to NMC guidance, nurses are only permitted to conscientiously object to

procedures that involve abortion or assisted reproductive technologies (NMC, 2015b) ¹⁸. Therefore, they had no professional ground upon which to morally object to caring for patients who they believed were receiving futile and potentially inappropriate care.

End-of-life care was a common catalyst for moral issues amongst participants, as will become clear from the narratives reported throughout this chapter. Many participants described feeling angry because they believed they were participating in cases similar to these described - in which they felt care was futile, too aggressive and inappropriate thus serving to only extend patient suffering. This conflicted with their belief that nurses ought to help provide and facilitate a ‘good’ death for patients. A ‘good death’ was generally described as one in which patients were not suffering, free of pain and were surrounded by their family and friends.¹⁹ Participants saw aggressive and ‘futile’ treatment as a barrier to providing a good death, and this seemed to result in feelings of anger and frustration.

¹⁸ Under Article 4 [1] of the Abortion Act 1967 [Scotland, England and Wales] and Article 38 of the Humana and Fertilisation and Embryology Act (1990)

¹⁹ I discuss this in more detail in a forthcoming book chapter: Morley, G. Ives, J. Bradbury-Jones, C. Moral Distress in End-of-Life Care (in press) in Emmerich, N. Gordijn, B. Mallia, P. (eds.) Contemporary European Perspectives on the Ethics of End-of-Life, Springer (Philosophy and Medicine series) (Peer-reviewed)

Perceived futile care cases were not the only situations in which anger arose. Joyce seemed to become angry and indignant when describing the lack of support in her unit. Joyce describes how the poor layout of the unit, in combination with a lack of staff meant that it was difficult to leave the bed-space and get help when required. Although it is not stated, the implication of this inability to get help was a reduced quality and safety of care. Anger seemed to be associated with feeling morally constrained - Joyce was unable to carry out the level of care that she believed was required - because of institutional problems and was forced to provide a lower quality of care (moral wrong).

“I found that Band 6's [senior nurses] didn't take patients but that's purely because there weren't enough of them and even people on the Intensive Care course if there wasn't a Band 6 on that day then they might be team leading so I didn't think the juniors had enough support from senior staff in the environment that we were in because you were working two beds, two beds, two beds but if it was open plan there would be a senior staff member just two beds down from you or 3 beds down from you and you could feel comfortable asking questions but when you can't actually leave the room to go out, you have to wait for someone to come along or someone's on breaks because we have to wait for 3 way breaks so you could be left to yourself for a good hour and you can't actually leave the room to call someone, so in that sense it was quite challenging I think but it has made me aware of the support that is needed for people and you do see a lot of new starters leave because they're afraid, that says a lot about it if you can't get through the first 2 or 3 months of a job and you're fearful going home.” (Joyce)

Joyce also describes her perception that many new starters leave ICU because they seem to feel unable to provide the level of care they envisioned, were frightened of making serious errors and didn't feel supported. This finding has been captured in other studies, for example in a longitudinal study Maben et al. (2007) found that newly qualified nurses emerged from their training with a set of nursing ideals and standards to which they expected to practice. However, Maben et al. (2007) found that within two years, many of the nurses felt their

ideals had been compromised or crushed, leading to disillusionment, ‘job hopping’ or a decision to leave the profession. Participants in this study saw staffing issues as circular: a lack of investment in nurses meant units were often short-staffed and reliant on temporary staff; the high reliance on temporary nurses meant permanent staff continued to feel unsupported which made their jobs more stressful and contributed to their intent to leave.

5.2.2 Frustration

As with anger, frustration seemed to be associated with a sense of injustice, feeling constrained and implicated in carrying out a moral wrong. In the following quotation, Elizabeth describes how the healthcare team were prevented from carrying out what they perceived to be right because, according to Elizabeth, although the healthcare team were united in believing life-sustaining treatment should be withdrawn, the family disagreed.

“...that was I think a very distressing experience for everyone involved because the family, her large family, were absolutely insistent that we give her like everything and we just carry on and she was for everything ...and I think we as a medical team and as a nursing team we came together very early on and was like we shouldn’t let this lady will be on a ventilator and unresponsive for the rest of her life... and that the best thing to do ethically would be to withdraw care and everyone agreed but obviously the family didn’t agree and that was – that was very, very traumatic for everyone involved because it suddenly became them and us.” (Elizabeth)

In the next quotation, Danielle describes feeling that nurses and doctors are often singing from “*different hymn sheets*” and again, the moral catalyst is a case of perceived futile care. Danielle suggests that nurses and doctors hold different values; she thinks that nurses are more accepting of death and so able to admit when care is futile, whereas doctors view death as failure and are

therefore unable to accept that care is futile and are reluctant to withdraw life-sustaining treatment.

“it’s difficult because I think a lot of the time we feel like we’re singing from two different hymn sheets because we, I feel like we can see the death before either the doctors can see it or they will accept it. And I think the thing is what’s different with doctors and nurses is that doctors see a death as like a failure whereas, like, I would see a good death as a really positive thing, not a bad thing. Whereas I would be more upset by, like, a death that wasn’t well managed.” (Danielle)

Both Elizabeth and Danielle seemed to express frustration because of a moral conflict. For Elizabeth, the conflict was between the family and healthcare team, and for Danielle between the nurses and medical team. Many participants described moral conflicts between themselves and the medical team. They articulated the belief that whilst doctors valued the continuation of life at all costs, nurses valued the relief of suffering. However, their perception of these divergent values may have been due to a lack of communication and failure to understand one another’s responsibilities and roles. For example, some participants didn’t discuss the difficulty of making withdrawal/withholding decisions but discussed the belief that the medical team didn’t understand how it feels to provide life-sustaining treatment at the bedside and be in close proximity to suffering. Some participants expressed sympathy for medics who had to make difficult decisions regarding withdrawal of life-sustaining treatment but this didn’t seem to diminish their frustration and anger.

Frustration also seemed to arise in the context of moral uncertainty. Phoebe describes the frustration associated with treating a patient on extracorporeal membrane oxygenation (ECMO) and articulates uncertainty as she considers

the benefit of using an expensive and resource-intensive intervention for a patient she believes is unlikely to benefit. Phoebe discusses weighing the level of suffering with the potential benefit of further learning. Phoebe concludes by stating that many ethical decisions in critical care are rarely clearly right or wrong, and seems frustrated by this uncertainty.

“It's frustrating. It is frustrating. It's a bit de-motivating when you think how much money, time and effort is going into that patient to know that really they're not going to survive it, they're not going to get out of it ...but what they learned from putting that man on ECMO was so educational for other traumas on ECMO that now we're putting more traumas on ECMO and saving more lives in that way but then for every one of him, how many have we put on that haven't survived? But then those people would have died anyway, do you know what I mean? So, is that a waste of money and resources, could somebody else have had that as a resource, or, did we learn from that okay we can put this trauma on but not that trauma on? As with everything in Intensive Care, nothing is ever black and white as much as I would like it to be....” (Phoebe)

Throughout this chapter, I am using quotations from participants and suggesting they portray one or two predominant emotions. However, I acknowledge that we often experience a mixture of many different emotions that sometimes conflict and it can therefore be difficult to determine predominant emotions. Although the next quotation is lengthy, it represents this mixture of emotions that many participants seemed to express, a combination of anger, frustration, exasperation and sadness.

“...feeling like you are dragging someone out that you're causing suffering to them and their family for no particular reason, but at the same time not really feeling equipped to know what that means or what quality of life means. So, I think yeah that causes me a lot of distress, I really feel in my gut that I'm not doing any good for this patient, like I'm not – I'm not helping them in any way, even though I'm keeping them alive I'm not – not making them better. I'm just extending whatever sort of purgatory they're in. And no-one seems to know, no-one can tell me

like what's going to happen... and you feel like you've got quite a good idea of their clinical outcomes but just a bit like, yeah I think that what are we doing? Why are we doing this? Is this- I'm not making, I'm not doing, I don't feel like I'm doing my job as a nurse, I'm not making them better, I'm not helping you, I'm not comforting you, I'm not. I'm just ticking you over constantly and there doesn't seem to be an end, no end to like parents or your partners or your children's suffering because we're just keeping you going and going and going and there's no end to it. Er, like – like limbo and I think that – that's what causes me a lot of distress because you do feel like because then that naturally leads you to a place where you're like 'oh well like should we not just kind of let them go... like would that not be the nicest thing to do'? And then you're like 'well yes and no because then you don't know exactly what their outcomes are' and you don't really feel equipped to like make such a momentous decision about someone else's life and you're just like... so I'm between just ticking this person over in this horrible sort of process of life that doesn't seem to resemble it and it's really grotesque to look at and really macabre and family are just coming in and seeing their loved one attached to all this stuff, all the time and they don't resemble a human being let alone the person they used to be and you're like, this is cruel... I feel like I'm playing with a human like they're no longer a person they're just organs and tissue and you're like playing Lego with them, you're like 'oh I wonder what happens if we stick this tube in here and maybe rewire this, maybe that will work'. And you get to that point a lot of the time with the patients where you're just like I could just play with their ventilator settings like okay yeah CO2's gone up a bit but it doesn't really mean anything... you're like playing a really, really messed up game of operation. This is all wrong, this is so wrong. And then when you like okay well then should we withdraw or should we start talking about palliation in that case because we've not got any kind of like goals set in real world... And then you've got that decision that you've come to the feeling that it's wrong to be doing what you're doing but then you feel like it's kind of wrong to be making that decision because you're not making it, like you're making it from a place of very educated guessing but it's still like that small percentage of guess work in there and you're just like there is no right answer ...” (Elizabeth)

Elizabeth seemed to express a mixture of emotions as she describes feeling unable to decide whether providing life-sustaining treatment is right. In many ways, Elizabeth's narrative echoes Amelia's in the previous section. Amelia talked about the feeling of torturing patients in a “*weird dystopian*” world; Elizabeth describes ICU as akin to “*purgatory*” and like a game of “*Lego*”. These visceral and dramatic descriptions suggest the depth of emotion that

caring for patients in critical care evokes, and the deeply philosophical questions these experiences highlight, such as what is living and what is death? When is a treatment good or bad? Who has the right to decide when to withdraw life-sustaining treatment? Often participants were reflecting upon experiences that had happened several months prior, which suggests these questions continued to haunt them. Elizabeth considers these philosophical questions as she attempts to weigh potentially futile care with the uncertainty of prognostication and the finality of decisions to withdraw life-sustaining treatment. As with previous participants, Elizabeth seems concerned that she is perpetuating suffering by providing potentially futile care. However, the way Elizabeth goes back and forth in her narrative suggests she is uncertain and finds these questions dilemmatic: the morally preferable option is not clear. As with Phoebe, Elizabeth doesn't describe these ethical decisions as obviously right or wrong and so although she seems to feel constrained, she also seems to be frustrated and upset by the moral uncertainty these questions create.

I have suggested that when participants expressed anger this seemed to signal that they felt implicated in a moral wrong and was more commonly associated with a feeling of knowing the right thing to do, constraint and conflict. (I refer to these collectively as 'moral events'). Whereas, frustration seemed to be felt not only during these moral events but also when participants felt unable to decide, and so during moral uncertainty and dilemmas. In Table 12 (p.230), I have listed the emotions that seemed to be predominantly associated with each moral event. As I have mentioned, because emotions are often multiple and conflicting, and individuals respond to situations and experiences in different

ways, it must be noted that these are generalisations. Nonetheless, they are general patterns which have emerged from the data and upon which I build.

5.2.3 Guilt

Many participants described feeling guilty about their actions and inactions both during moral events and afterwards. Guilt and regret seemed, in particular, to have residual effects as participants described feeling these emotions for a long time afterwards. In the next quotation, Beth describes feeling guilty despite also expressing the belief she had done the right thing. Beth was caring for a patient who was dissenting from continuation of life-sustaining treatment and the healthcare team were conducting capacity and psychiatric assessments, and consulting with the legal team regarding whether they could legally withdraw life-sustaining treatment. However, whilst all of this was taking place, Beth and the rest of the nursing team were still required to continue providing life-sustaining treatment in the interim period. In the first quotation, Beth describes the immediate guilt she felt performing the required interventions. In the second quote, Beth describes the continuing anguish she experienced following the event. This suggests that for Beth, feelings of guilt continued to linger after the initial event as she continued to feel morally uncertain.

“I could see her distress and that she was so upset and it just made me feel guilty. No matter how right I knew I was on a practical level, you know, seeing how it made her feel, it just, made me feel guilty.” (Beth)

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“I still felt guilty because I knew she didn’t want me to do it, and as I say we are taught from day one about autonomy and about capacity and consent, and I knew she had capacity and technically she was not giving me consent to suction her via her trache[ostomy] but it’s that very hard grey area of best interests, you know? I’m not allowed to just allow you to

plug off, so it is difficult. It's hard when you try to say right and wrong which is the difficult part of it but I knew I needed to do these things but it didn't stop me from feeling guilty about it." (Beth)

In this experience, guilt seemed to be associated with moral constraint and moral uncertainty. Beth described feeling constrained because of her professional obligation to continue providing life-sustaining treatment (in this example, suctioning an artificial airway) but she also expressed uncertainty because this conflicted with her personal feeling of relational responsibility to the patient; and Beth seemed to feel residual guilt because she was uncertain about whether she had acted in the patient's best interests and done the right thing.

In the next quotation, Lily describes feeling constrained and uncertain about whether she did enough to advocate for the patient and her subsequent feelings of residual guilt. Lily discussed caring for a patient she believed needed increased medication and sedation for anxiety but Lily felt that her suggestions faced resistance. Lily describes worrying about whether her attempts to advocate for the patient had been sufficient and seems to feel guilty because she worries she could have done more.

"I wanted to be more an advocate for the patient, to get these issues across but like I said sometimes something is already being done and sometimes people want to wait until this medication properly kicks in sometimes. If they see that someone is having anxiety then you have to wait for it to kick in but you know how long should you wait?... I think that is the down side of having ICU actually because you don't have much idea of what is going on in the different bed-spaces, you don't know whether your concerns are actually being taken seriously. ... I do feel sometimes that Band 5 [junior nurses] nurses are not taken seriously because I feel if I want to make a point I need to get a dark blue nurse, a Band 6 nurse [more experienced nurse] to support me and back me up in these kind of things and then I will be taken seriously and again it's not always the case

but it depends on the doctor who you are working with. But being a Band 5 I feel unnoticed in that sense and I think it also comes down to personality, like how you express yourself and I think in a way that's why I'm feeling guilty because I wasn't requesting enough and I was at the bed-space and noticing these things and maybe not requesting enough to escalate them to the team when I had the chance. I feel like despite working a few years my knowledge is never going to be the same as the doctors when it comes to pharmacology and things like that so sometimes when they offer something I agree with it but I feel I am not qualified enough to actually..." (Lily)

Lily describes the difficulty of being “*taken seriously*” as a junior nurse. She believes that some members of the medical team listened to and respected senior nurses more than junior nurses and to successfully advocate for a patient she needs a senior nurse to help her communicate with the medical team.

The duty of acting as a patient’s advocate seemed to be a deeply held commitment and responsibility which motivated participants to try and promote what they perceived as the best interests of the patient. This motivated them to engage in discussions and moral conflicts with other healthcare professionals. However, as Lily’s quotation illustrates, unsuccessful attempts or feeling unable to advocate could create guilt for participants. I will discuss advocacy again in the next chapter but for now the important point is that Lily seemed to express guilt and regret because of a perceived inability to effectively advocate. This may have been because of Lily’s lack of confidence to speak out (internal constraint), or a consequence of working in an environment in which she felt her opinion wasn’t valued and respected (potentially a real constraint or a perceived internal constraint). Nonetheless, Lily described feeling uncertain about whether she could have been more assertive and this seemed to cause her feelings of residual guilt and regret.

Both Beth and Lily described experiences in which they seemed to feel they had done the best they could and ultimately, done the right thing. However, they also expressed feelings of guilt and regret. Guilt seemed to be associated with moral constraint (despite their best efforts they still had to compromise), moral uncertainty (they doubted the rightness of their actions) and was felt initially and residually.

In chapter 3, I discussed Jameton's suggestion that moral distress should be divided into two parts: initial and reactive. According to Jameton (1993), initial moral distress consists of the feelings of guilt, frustration and anxiety one experiences when unable to act in accordance with one's beliefs due to an institutional obstacle; whereas reactive distress occurs because the individual failed to act upon their initial distress, and both initial and reactive moral distress occur due to a moral constraint. However, Beth and Lily's circumstances seemed to be more complex. Whilst there was a constraint present, both participants described feeling they performed the only available morally preferable action – Lily advocated for the patient and Beth continued providing life-sustaining treatment - but despite this, they continued to feel guilty because of their doubts and uncertainty.

Epstein and Hamric (2009) suggest initial moral distress ought to be considered moral distress, whilst reactive moral distress is a different phenomenon named 'moral residue'. Drawing on a definition of moral residue from Webster and Baylis (2000), Epstein and Hamric (2009) suggest that moral residue is "that

which each of us carried with us from those times in our lives when in the face of moral distress we have seriously compromised ourselves or allowed ourselves to be compromised.” (p.218) The lingering guilt described by participants doesn't seem to match this description of moral residue. Beth and Lily both seemed to suggest that to some extent they had acted in accordance with their beliefs. In Beth's case, although she felt personally guilty about continuing to suction the patient's tracheostomy, she felt this was the right thing to do and she had a professional duty to maintain the patient's artificial airway. In Lily's case, she described feeling she had advocated for the patient to the best of her ability but still felt guilty and worried she could have advocated more forcefully.

The experiences described by participants seemed to more closely resemble the moral residue originally described by philosophers Williams (1965) and Marcus (1980). Williams (1965) argued that feelings of guilt, regret and remorse signal a feeling of 'moral remainder' or 'moral residue' such that “even if we think we 'acted for the best', the phenomenon of a regret shows that it is a mistake to think that 'one ought must be totally rejected in the sense that one becomes convinced that it did not actually apply” (Gowans, 1987, p.14). Both Beth and Lily seemed to feel they had acted for the best despite the constraints that limited their agency and the persistent guilt seemed to be the most troubling emotion.

Williams (1965) and Marcus (1980) used the experience of moral residue as a phenomenological argument for the existence of genuine moral dilemmas (Kühler, 2012). They argued that guilt and regret suggests that one moral

requirement cannot completely cancel out another moral requirement. For example, the requirement to allow a patient to have a peaceful death doesn't completely cancel out the requirement to preserve life, and thus signals a 'genuine' moral dilemma. Indeed, many philosophers since have found this to be a convincing reason to believe genuine moral dilemmas exist (Tessman, 2015)²⁰. I will come back to this discussion in section (ii).

One might argue that the experiences described by Lily and Beth were not genuine moral dilemmas in the philosophical sense because there was a morally preferable option, they simply failed to identify it because they lacked the skills to work through the moral problem. However, this may be irrelevant. The experiences seemed to feel dilemmatic for the participants and guilt and regret were associated with both actions (continuing to provide life-sustaining treatment despite resistance vs. respecting autonomy but disregarding one's professional obligations, and potentially the law). If one accepts a phenomenological argument for the existence of moral dilemmas, then one ought to accept that these experiences constitute a dilemma for these participants because they *felt* dilemmatic. We may be no closer to 'proving' that moral dilemmas exist, but it seems that individuals do *experience* some moral events as dilemmatic.

²⁰ Whilst I am trying to draw a phenomenological distinction between moral dilemmas and moral conflicts, I am aware that I will not solve centuries of debate regarding the existence of moral dilemmas. I hope to make the more straightforward point that the emotions associated with 'moral distress' seemed to be experienced in both moral dilemmas and moral conflicts.

In the second excerpt from my reflexive research diary, I reflect upon the process of writing this chapter and trying to capture the empirical data.

Box 3: Reflexivity (2)

There were three different iterations of this chapter before I wrote this final draft. After writing the first draft and receiving comments back from my supervisors, it soon became clear that I had written predominantly about the causes of moral distress. I wrote extensively about the ways in which end of life care, poor team dynamics and a lack of communication caused moral distress for the participants. However, because I was focusing on the causes of moral distress, the chapter remained question-begging. “Poor team dynamics and a lack of communication meant that nurses were excluded from decision-making and caused them to feel morally distressed”. “Yes, but what is moral distress?”

Undoubtedly, the causes of moral distress are important, and exploring the causes of moral distress will help us to respond and manage moral distress. However, they do not inform the concept itself. I went back to the interview transcripts and started to look more closely at the various emotions that I had coded. As I started to re-write this chapter and explore the emotions that had been described, I realised that they illuminated and explained the concept. I never thought that the findings chapter would be presented in this way - with

so much emphasis on emotions - but they help us to understand what experiencing moral distress actually means and by identifying the emotions we can explore the circumstance in which they arose and identify the causes of moral distress.

5.2.4 Regret

Regret seemed to suggest a feeling of loss and was often described alongside guilt. In the next quotation, Isabelle describes the regret she experienced after discussing palliative care with the patient's partner and medical team. Isabelle discusses thinking that the terminally ill patient was articulating her wish to end life-sustaining treatment. Motivated by her responsibility to act as the patient's advocate, Isabelle discussed the patient's wishes with the medical team, and they initiated sedative therapy. Isabelle raised the issue of palliative care with the patients partner but he became angry. She describes how this, in conjunction with some of her own personal problems caused her to **"burn out"** and seek counselling.

"I think that day I came home fuming as opposed to devastated just thinking, and guilt, feeling so guilty ... I thought okay that just happened, that was just intense, must have been a tiring day and you know I just moved on and I think it was afterwards that I realised, not pinning it all to that event but I think it really, it just, I don't know I felt like I left a part of me in that side room that day for some reason, or like it left a scar on me that I am never going to forget and I felt like it was the right thing to do but it genuinely, I don't know it makes you think about things that you wouldn't see otherwise....
...like because you spend so much time at the bedside you end up getting to know the patient more than the doctors often, or the rest of the team.
And then you have to stand up for people, for patients, I find... and sometimes that is, you know you can be torn thinking you know, is this right? Have I gone too far? Am I just going crazy? Am I just tired? And not just for life or death situations but just in general, am I pushing it too

far like standing even for them thinking I know this isn't all that you want but I am going to do it because I know this is what you need right now, and even then you can feel like you know, am I doing the right thing? Is this really the right thing to do? And it brings some sort of tension that you can't quite explain or you don't really think about it you just come in and then you leave work but I genuinely think it leaves a mark on you in some way so it does affect you in some ways that you couldn't quite explain...

...did I misunderstand, did we all misunderstand this? What is the right thing to do? What's my job? Is it to look after her or the family, or both? And in that case what do I do, when both interests seem to be different? Yeah, I think that was the main thing, just and if it was the right thing why does it feel so hard and so painful, because often if you do the right thing you go home satisfied thinking I have done what I am supposed to do... That day was probably the worst day where I didn't feel like I had done the right thing and looking back I am convinced it was the right thing, it just did not feel like that and for a long time it still didn't feel like that.” (Isabelle)

Isabelle seemed to find it difficult to make a moral judgement as she asks multiple rhetorical questions. She suggests that moral dilemmas bring “*some sort of tension that you can't quite explain*” and she seems almost tormented by moral uncertainty. Isabelle describes the feelings of regret, guilt and loss that she experienced stating “*if it was the right thing why does it feel so hard and so painful*” and feeling as if “*I left a part of me in that side room that day... or like it left a scar on me that I am never going to forget*”. I suggest that this feeling, as Williams (1965) argued, signals that Isabelle experienced a ‘genuine’ moral dilemma. Although she carried out the action she believed was morally right (by raising the issue of palliative care with the patient’s partner) she also describes the pain this caused. This left Isabelle feeling uncertain and conflicted about whether she should have prioritised her obligation to the family rather than to the patient. She describes the lingering feeling of regret as she wondered for a long time whether she had truly done the right thing. Isabelle’s quotation highlights how deeply some moral experiences can affect individuals, and the

difficulty of articulating the lasting effect they can have. As with guilt, regret seemed to be an emotion that endured beyond the initial moral event.

In the next quotation, Grace suggests regret and guilt are almost inevitable, stating that it is the *“nature of the beast”*. Grace seems to suggest that truly distressing events are those that cause moral uncertainty and leave you questioning.

“I don’t know, the nature of the beast sometimes, is that you think like there’s always an element of like, kind of, ‘What more you could have done? Could I have done this better? Did I... put my opinion across enough? Did I advocate for my patient appropriately?’ That kind of thing ... but it’s the stuff that really stays with you and then makes you think about things and it is... I find the more kind of responsibility you have in a role, the more you start questioning maybe morals and stuff because when like I was kind of first starting out as a bedside nurse, you’re kind of – you’re learning – you’re almost learning the trade, you’re learning how to look after the patients appropriately and ... you’re doing what is told because, you know, you, you haven’t got the experience and stuff and then the more experienced you get, you start thinking, you know, ‘Oh well, maybe we could do this as well’ and, you know, that’s great and then... going into different roles, like... doing – I mean doing Outreach senior [nurses that provide assistance for deteriorating patients] was just like every single shift, it felt like you’re questioning, ‘Is this the right thing to be doing?’ And a lot of that would be whether we should admit someone to the ITU or not but then it’s very difficult to say, ‘actually, we shouldn’t admit them’. Like, what are the reasons?... and that’s kind of where you have to delve a little bit deeper into the patients and think about the quality of life and that kind of stuff and actually what they’re presenting complaint is but I found that really difficult, especially when... like again, with – there would be differences in opinions between the Outreach Nurses and the Registrars [junior doctor undertaking specialty training] ...I found that role particularly difficult with, with that kind of thing about doing the right thing for patients and there being a real difference in opinion.” (Grace)

Grace also discusses her belief that more experienced and senior nurses tend to question ethical issues more. Researchers have explored whether there is a correlation between years of experience and moral distress, and the findings

have been variable and conflicting. For example, Corley et al. (2005), Allen et al. (2013) used the MDS and MDS-R to measure intensity and frequency of constraints believed to cause moral distress and found that less experienced nurses reported higher levels of 'moral distress'. Woods et al. (2015) found that younger (and presumably less experienced nurses, although this is not reported) also reported higher levels of moral distress and they hypothesised that this was because their reported level of 'ethics preparation' was higher, suggesting they may have more awareness of ethical issues. Whereas Hamric et al. (2012) and Dodek et al. (2016) found that moral distress scores were higher amongst more experienced nurses and suggested that this was evidence of the 'crescendo effect'. Epstein and Hamric (2009) suggest that repeated experiences of moral distress create a moral residue which builds over time into a crescendo.

As this research is qualitative it is not possible to measure and compare reported levels of moral distress in the same way as those just mentioned. However, examining the demographic information of participants in this study, similarly this information tells us very little: the majority of participants were junior nurses ($n=12$) but the majority were also relatively experienced ($(n=12)$ 5-10 years of experience)). Taking into consideration the motivations and ability of participants to take part in research, for example younger and potentially less experienced nurses may find it easier to participate than older nurses because they do not have to consider issues such as childcare. This highlights how it is problematic to try and predict moral distress based on demographic factors.

Nonetheless, there seems to be a difference between emotions felt ‘in the moment’ during moral events and the residual emotions that lingered afterwards. For example, Beth described feeling guilty both during the moral event (by suctioning the patient’s airway she felt implicated in causing suffering) and afterwards, as she also described feeling uncertain and conflicted about whether fulfilling her professional duties had been the right thing to do. The residual feelings of guilt and regret seemed therefore to be associated with continued uncertainty regarding whether she had done the right thing, and seemed to signal moral residue as described by Williams (1965) and Marcus (1980). This suggests the moral event was experienced as a moral dilemma for Beth.

5.2.5 Sadness/Upset

Feelings of sorrow and sadness were commonly expressed emotions, and sadness seemed to be experienced primarily during moral conflicts and dilemmas. As Beth discusses in the next quotation, nurses, patients and families experience emotive situations together and because they are in close proximity for long periods of time they can form intimate relationships. When there is an emotional connection this seemed to make managing moral conflicts and dilemmas more difficult. For example, Beth describes how she finds it difficult to detach herself and adopt the “*practical*” and “*logical*” position which she believes is required for clinical-ethical decision-making. Many participants discussed feeling emotionally invested in patient care and outcomes, and the effects this had on their own mental wellbeing. Beth describes feeling “*wrapped up*” in others’ emotions which is “*difficult*” and “*draining*”.

“I think when you’re at the bedside for someone, and I guess nurses say this quite a lot. When you’re the person that’s there with them for twelve and a half, thirteen hours a day, it’s very difficult not, and you maybe shouldn’t, but it’s difficult not to get wrapped up in how they feel. Visiting teams, though I’m very sure they were doing their very best for her. I don’t think they kind of succumb to that the way we would because you’re feeling the full force of someone’s distress...all day. You’re feeling the full force of their family’s distress for most of the day so it’s really hard to kind of take that step back and be more practical or more logical in your thinking. You know, I wasn’t, I wasn’t crying at the bedside, I wasn’t in a state, but I felt it. And there’s obviously, you know, that didn’t leave the minute you walked out the door, it stayed with you, and feeling that for hours and hours on end for a day is draining! It’s draining on anyone! ...yeah... it’s difficult. It’s one of those difficult scenarios where I don’t think anyone did anything wrong but it still didn’t feel right in the end.”
(Beth)

Many participants became tearful and cried during interviews. When this occurred, I gave participants time to either discontinue, pause or stop the interview and afterwards I ensured participants were aware of the support services available at their hospital trusts (as listed on the participant information sheet). No participants chose to discontinue and reflecting on this, I suggest it was because these traumatic events had motivated them to take part in the research. It felt as though often these events had been defining moments in their nursing careers and they wanted to share them.

Participants discussed framing moral problems in terms of what they would want for themselves and their families in similar circumstances. In the next quotation, Amelia mentions the Golden Rule, ‘do as you would be done by’ (Matthew 7:12)²¹.

²¹ New Revised Standard Version, www.biblegateway.com, accessed 04/06/18

“I think it comes from what you would want happen to you. You know like, do as you would be done by...treat people as you want to be treated...all of the platitudes. But I do think that most nurses feel that very deeply. I hear everyone say it all the time, it’s like “Oh if this was my Dad, or if this was me I would...this is how I would want to be treated...I would want to have dignity and respect and to be treated with love and care...” (Amelia)

Although Amelia mentions this commandment, participants generally didn’t seem to appeal to rules for moral guidance but instead seemed to consider their own relationships, values and desires as a guide for their professional lives. Participants may have reasoned in this way because they felt an emotional connection to patients and families, or perhaps because they didn’t have the ethical training to work through moral problems in a systematic way. This is not to critique moral judgements based on relational considerations, but rather to highlight that relational judgements may not be sufficient. To reach ethically justifiable decisions, healthcare professionals need to consider not only what they might want in similar circumstance but to consider this in the context of patient’s wishes and values. As Walker (1989) suggests, moral understanding consists of a “shared process of discovery, expression, interpretation, and adjustment between persons” (p16). This means discussing one another’s moral values and reaching decisions based not only on the clinical picture but based on the patient and families wishes and their responsibilities and relationships between one another. Walker (1989) coins this the “expressive-collaborative model” which positions moral life within the continuing negotiation between people and recognises that relationships and responsibilities can pull our moral values in different directions (p.67). Therefore, reaching moral understandings

between individuals requires continuous negotiation in light of each other's values, norms, principles, maxims and guidelines (Walker 1989).

In the quotation below, Kayleigh describes a decision-making process that is more akin to the process suggested by Walker (1989) as she considers her own and the patients values and wishes. However, there does appear to be an epistemic and power differential that could impact decision-making, as Kayleigh suggests that the family may not be able to *“fully understand”* a prognosis.

“...discussing it with the family and seeing what someone would have wanted, seeing if that's the right decision because if there is still stuff we can do and they can turn the corner, then I'm all for doing it but if the end result is not going to be...it's difficult because a little aspect of it is what would I want and what would you as a person want out of life and I would never want to be a brain dead cabbage that's trach'd in a bed who can never communicate with anyone ever again; I'm technically, technically alive but I don't have any communication, I think that sometimes might probably affect my opinion of what we should do but I don't always think that loved ones and relatives fully understand when someone says they're going to have, they're never going to be the same again, they'll never have any communication skill or be bed bound forever; I don't think they always fully understand what that means...”
(Kayleigh)

I will explore more fully the additional factors that may impact one's moral experiences in the next chapter. For now, I want to highlight that participants seemed to describe how proximity between themselves, patients and families within an emotive environment brought them together and they felt that they shared an intimate bond. Participants described how this intimacy made managing ethical challenges particularly painful and upsetting.

Feelings of sadness were also associated with experiences that weren't morally, but instead emotionally, difficult. In the next quotation, Amelia discusses a tragic situation in which a young patient suffered a catastrophic head injury and donated her organs. Unprompted, Amelia stated how in the context of moral distress, this experience didn't seem relevant and went on to discuss an experience that she did feel was relevant. I went back and spent a few minutes exploring this experience with Amelia but it soon became clear that there were no difficult ethical issues involved in the case. Amelia described how organ donation had been the patients and families wishes and the event had simply been tragic. Amelia then discussed a second experience she believed was relevant to the concept of moral distress and described an experience in which she was required to withdraw life-sustaining treatment from a patient.

“I think the first one that ever really kept me up at night, was a young patient. This is in Neuro ICU. She had a big bleed and was brain stem dead, and we did organ donation with her. She was a donor. Her family gave everything. It was the most amazing thing that I have ever seen in my whole life, cos I was there from the minute she came in, it was over the weekend, over 2 night shifts. So there the night she came in, and then I was with her when they took her organs away, and I still think about that all the time. Just because it was an amazing...but it was, a... truly heart-wrenching time. Like her family, were not even human beings anymore really. They were just completely, I dunno, they were a mess, it was terrible.

I mean if we are looking at the context of moral distress, I don't feel anything about that, it is just something that has stuck with me.

And then, something more recently was an old lady...and she was with us because she'd had a heart attack and we had her on Noradrenaline [a life sustaining medication to support the cardiovascular system], and then we did the family meeting and then her daughters decided that we should switch everything off, because she was very old, she had dementia, she didn't know what was going on and she wasn't going to leave the hospital because we were just keeping her alive with Noradrenaline.” (Amelia)

Many participants began with an ‘emotional distress’ story and I initially wondered whether this was because the emotional issues were more troubling than the ethical ones. Indeed, for a small number of participants it wasn’t until I started asking questions about the moral issues that they began to discuss them. Upon reflection, I think that some participants were using their emotional distress stories as a mechanism for opening-up and developing trust with me. Whereas other participants came ready and prepared with stories that were morally fraught. Nonetheless, the emergence of these ‘emotional distress’ stories helped to highlight the difference between emotional distress and moral distress, which I suggest in chapter 8 require different responses.

Amelia and Kayleigh both described feeling sad and upset during moral conflicts and dilemmas. They described empathising and feeling sorrow for patients and families facing difficult moral problems. They also seemed to feel morally uncertain due to a conflict between their intuitive and rational cognition. In the next quotation, Amelia discussed her rational belief that a ‘good’ death is morally preferable for patients but describes feeling unable to reconcile this belief with the very visceral feeling that she had intentionally ended a patient’s life (see next quotation).²²

²² Amelia discusses withdrawal of life-sustaining treatment here in terms of intentionally killing, however, I want to make it clear that she is describing how the experience made her feel. Examining the rest of the dataset, Amelia discussed how the decision to withdraw life-sustaining treatment had been made by the consultant in conjunction with the patient’s next-of-kin. Earlier in Amelia’s narrative, she describes how the consultant very clearly explained the patient would die following the

“...even though I think of it as a good day, I still think about it, it’s not left me. I still think about the fact that I ended a person’s life. I just think that there’s no way to get around that is there? It’s like, it was a good thing and I did it for the right reasons but it’s still a thing that I did and I’ve never done that before. It was an intentional thing. I intentionally ended a person’s life and when you say it like that...how can those words come out of my mouth? I just don’t think that’s an experience that many people have, and then to have to...to have to reconcile it, so with normal morals...hospital morals I guess...maybe its two different things. I just think it’s shocking. It’s a shocking thing”. (Amelia)

Amelia seemed to feel conflicted between her intuitive (personal sense of right) and rational (professional sense of duty) cognition, producing a feeling of moral uncertainty. Intuitively, she seemed to feel that helping someone die was morally wrong, whereas rationally, she believed that her actions were bringing about good as she allowed someone to die with dignity. This inability to reconcile her beliefs and emotions seemed to create moral uncertainty, causing her to feel sad, upset and distressed. These feelings are interesting given that Amelia also discussed believing that ultimately, she did the right thing.

Looking back at Beth’s description of her feelings of guilt and regret in the previous section, she also described experiencing moral uncertainty because of her personal and professional responsibilities as she tried to decide whether she should suction the patient’s tracheostomy. Many participants’ initial judgements seemed to be a result of their intuitive processes – they describe

withdrawal of Noradrenaline and the family understood this and were able to be with the patient when she died. Despite the wording of the quote, at no point did Amelia disclose any activities that might be construed as illegal or reportable.

how inside they felt like they knew the right thing²³ - but that they had to align this with their professional responsibilities through reason and rational processes.

This distinction between intuitive and rational processes has been employed by Tessman (2015) as another phenomenological argument for the existence of genuine moral dilemmas. Tessman (2015), using empirical research from moral psychology (for example Haidt (2001) and Cushman et al. (2010)) argues that this dual-process model of moral judgements in which the intuitive system conflicts with the reasoning system gives rise to the feeling that “moral life is, through and through, dilemmatic” (p.97). Tessman’s argument is that this inner conflict can give rise to the feeling, articulated earlier by Isabelle, “*if it was the right thing why does it feel so hard and so painful*”, of inevitable moral failure. Moral failure, Tessman (2015) suggests, occurs when we find ourselves in impossibly complex ethical environments (such as critical care) and despite the rational feeling that we have done right, we still feel as if we have failed. Indeed, whichever option Amelia chose she seemed to face ‘unavoidable moral failure’: either withdraw life-sustaining treatment and feel she has hastened death, or don’t withdraw life-sustaining treatment and feel the patient is continuing to suffer. As with the feeling of moral remainder, the feeling of unavoidable moral failure, according to Tessman (2015) signals the presence of a moral dilemma.

²³ One might suggest that participant’s discussion about how they feel ‘inside’ is a reference to their sense of moral integrity, especially as moral distress has been defined in terms of this concept. However, participants did not discuss their experiences in this way and integrity did not emerge as a code during data analysis.

Sadness seemed therefore to be associated with moral dilemmas, as participants expressed sadness and loss due to unfulfilled moral requirements, and similar to guilt and regret, sadness could be felt long after the initial event, haunting participants for several months or even years afterwards.

In the following extract from my reflexive research diary, I reflect upon an interview in which sadness was one of the participant's predominant emotions and how I tried to balance respect for the participant's emotional state with the research process.

Box 4: Reflexivity (3)

Reflections post interview

The participant's young child was in the house and she looked really tired. She said she had been working the previous two days so immediately I felt very aware that she might be lacking in emotional energy. Indeed, she became quite upset early on in the interview and so I felt that I ought to tread carefully and allow lots of time and opportunities for her to pause or stop if necessary. I do think that this affected the way I conducted the interview slightly. Whereas with some of the other participants I had adopted a more challenging and Socratic style of questioning, in this interview I didn't want to probe any inconsistencies too deeply because I felt the participant simply didn't have the emotional reserve.

Reflections during data analysis:

Key Words/Key Themes: communication; futile care; decision-making; withdrawal of life-sustaining treatment; belief in 'good' death

She seemed very attuned to other people's suffering and she cried recalling how the wife of an elderly gentleman who was dying in ITU had to wait an extra day for life-sustaining treatment to be withdrawn because of delays in decision-making and communication.

As with other participants, she seemed to be experiencing moral uncertainty and inner conflict- she described feeling like she was participating in suffering because she was nursing patients that she believed were receiving futile care- but she also felt that this was her job and if she wasn't doing it someone else would be.

She seemed to feel that her opinion was not valued and this is particularly interesting when contrasted to the previous participant's narrative. This participant was more senior and seemed to be more confident than the previous participant but she also seemed very reserved and aware of her own limitations. I can relate to this feeling and I wonder if, like me, she can sometimes become dejected and so instead of fighting she becomes upset. She may be painting a bleaker picture because many of her recent experiences had been negative but at the same time I feel like she is being honest with herself and was under no illusions. Whereas I felt like the previous participant wanted to convince herself that she was a valued member of the team and as a result there were lots of inconsistencies in her narrative.

5.2.6 Torn

Some participants also described feeling torn and conflicted. Similar to previous participants, Liam provides a visceral description of how moral distress made him feel, as he describes his belief that moral distress is capable of tearing a person apart.

“Being torn....between what should be done, what can be done, what you would want for that person as much as what they would want. That feeling as I say of being ripped apart as to what you believe. I suppose that's sometimes the whole point isn't it, it's not supposed to be about necessarily what we believe... that's the confusion of your ethics with the situation.” (Liam)

Liam discusses his mistrust of some surgeons and feeling suspicious of their motives when it came to treatment plans. Liam worries that patients receive aggressive treatments because surgeons don't want to damage their mortality figures, rather than because continuing treatment is in the patient's best interests. Perhaps because of this mistrust, Liam seems to believe that when making moral judgments regarding patients, healthcare professionals should set aside their own beliefs to focus on the patient's best interests. Liam's feeling of moral uncertainty also seems to be because of a conflict between his personal and professional beliefs which culminates in feeling torn during moral events.

Feeling torn seemed to be commonly associated with moral uncertainty and dilemmas and was experienced when participants felt unable to decide which moral requirement ought to be satisfied. In the next quotation, Max also articulates his uncertainty about making decisions for patients. Max describes caring for a patient who was awake but supported by an intra-aortic balloon pump (IABP) because of heart failure. The medical team, in partnership with

the patient made the decision to sedate the patient and withdraw the IABP knowing that the patient would likely die because of his dependency on it. This experience raised a lot of questions for Max as he struggled to grapple with deciding whether this was the right thing to do.

“When they become more complex sometimes it's well we could use this machine to support them but we won't get them home on that so what are we going to use next? What are we using this to get to? Where are we heading? Will this patient recover? Will they need some other form of support or are they going to die? If they're going to die is it right that we carry on doing this? And that can be quite bizarre when the patient is on the chemical support and they are awake and talking to you in the bed, you know that can be very bizarre... so they sedated him and we withdrew treatment. I was looking after him at this time... that's a really, really hard concept to get my head around.” (Max)

Some participants employed what I have coined the traditional ‘moral distress lament’. This has been noted in some of the literature as a sign of moral distress, phrases such as “Why are we doing this?”, “[I] don’t get it” (Rushton, 2006), and “This doesn’t make any sense; why are we continuing to do this?” (Ulrich et al., 2010). These phrases are taken to show the moral agents feelings of powerlessness because they are unable to carry out what they perceive to be as the right thing. Some participants certainly used the moral distress lament in this way. However, other participants seemed to be expressing exasperation and frustration because they were unable to decide what to do. The distress seemed to occur because they felt torn, conflicted and uncertain rather than just constrained.

5.2.7 Powerlessness

Some participants accepted the limitations of their role, whereas others described feeling powerless, especially when it came to clinical-ethical decision-making. It may be argued that ‘powerlessness’ is not an emotion in itself but rather an amalgamation of other emotions, and indeed it seemed to be very often associated with frustration and anger and predominantly occurred during moral conflict and constraint experiences. Nonetheless, it was a feeling that was very often mentioned by participants when recalling their ethical experiences and therefore its inclusion is justified on the basis that it was prevalent in the data.

In the following quotation, senior nurse Olivia describes her belief that the decision-making hierarchy constrains bedside nurses, causing them to feel powerless because they are obligated to continue providing life-sustaining treatment even if they don’t think life-sustaining treatment is morally justified. Many participants described feeling the hierarchy acted as a moral constraint, making them feel powerless. However, this statement from Olivia is particularly interesting because she had the most senior role of all the participants, and yet also seemed to feel powerless, stating *“I agree, I think what we're doing is wrong but we're not in the position... we don't make these decisions”*.

“The nurses find it distressing that we've got someone like that here for 3 weeks and you go in and it's futile and you feel like you're being cruel and this gentleman is incontinent and his skin's falling off and it's getting infected and you want to say let's stop, let's stop what we're doing, but the doctors don't and that's what I think I find really, really difficult, you know, when you're at the bedside and you see the nurses and they come in to the office and they say 'I find this really, really hard' and I say yes I

know and I agree, I think what we're doing is wrong but we're not in the position... we don't make these decisions and I think we do try to take on board where they're coming from, especially as senior nurses you have to be there to explain, not justify what the doctors are doing, but you have to back up and say the doctors are doing this, this and this because this is what they think is in the best interests - no we don't agree but we have to work with them.” (Olivia)

Some junior participants reported feeling like senior nurses were respected and had more power, and believed they were able to initiate change or influence decision-making (for example, Lily in section 5.2.3, p.200). However, Olivia didn't seem to feel she could affect decision-making and seemed to adopt a passive rather than active role. She even suggests that none of the nurses could alter decisions regarding treatment plans.

Epstein and Hamric (2009) have suggested that powerlessness ought to be considered an internal constraint because it is perceived rather than actual. Indeed, there may have been several actions Olivia could have taken to alter the course of action. However, one's perceived ability to initiate change may be dependent upon the institution itself and the extent to which they feel empowered, valued and respected. I will discuss how these additional factors mitigate or exacerbate participants experiences of moral distress in the next chapter.

Natasha, a junior nurse, also expressed feelings of powerlessness similar to Olivia. Natasha describes characterising an experience as 'moral distress' because of feeling powerless. Natasha was responsible for continuing life-sustaining treatment for a patient who was intermittently declining care and she expressed frustration because she felt uncertain about what to do, whether she

should respect the patient's refusal or continue providing life-sustaining treatment. In this quotation, Natasha states how irrespective of her decision, she would have remained powerless anyway because it was not her decision to make, it was the doctor's.

“I think definitely with the lady from yesterday and the gentleman was moral distress because you kind of feel powerless to do anything and it's not your decision to say yes or no or withdraw or continue or... obviously with the gentleman it was his decision that he didn't want certain aspects of care and it was the doctor's decision to try and continue and I felt a little bit like piggy in the middle like trying to listen to the patient and trying to listen to the doctors...” (Natasha)

It is unclear whether Olivia and Natasha engaged in moral conflict and raised their concerns with the healthcare team, or whether they experienced moral tension – feeling they knew the right thing but didn't speak up. Nonetheless, even if they had engaged in conflict, it is likely their feelings of powerlessness wouldn't have subsided because their position in the decision-making hierarchy meant their moral agency was reduced. Liaschenko (1995), using a term first coined by Hobbes (1991), labels nurses 'artificial persons' because they are charged with the responsibility of speaking and acting on behalf of others (doctors and patients) and yet lack control. As Liaschenko (1995) states, “the central point...is that the person doing the speaking or acting is not the author of the actions.” (p.186) It is this lack of control over their actions that seemed to produce the feeling of powerlessness often expressed by the participants in this study. To summarise, powerlessness seemed to occur during moral constraint, moral tension and conflicts.

5.2.8 Stress

Many participants discussed feeling stressed because of their experiences, and they discussed symptoms commonly associated with stress such as difficulty sleeping and nightmares. It may be stress that culminates from the various experiences and produces the physical effects of moral distress that have been highlighted in the literature (for example, Hanna (2004)). In the next quotation, Chloe discussed the nightmares she experienced when she first started working in ICU because she worried her practice was unsafe and felt she was not adequately supported. This links back to the resource issues discussed earlier in the chapter, and the perspective that many nurses leave critical care because of fear and lack of support.

“I was always scared. I had nightmares every night for six months, like I didn't sleep. I would wake up in the night shouting, thinking I was naked, no one was watching my patient, I was naked in the bedside, someone had put my alarms on silent and my patient was arresting. ... just the craziest of nightmares and, you know, until I felt comfortable and safe and confident in my own practice, then I would never question anybody else.”
(Chloe)

The moral issue is not explicit within Chloe's quotation, but arguably organisations are morally responsible for staff wellbeing, and this constitutes a moral event. Many participants described the emotional strain of working in an emotive environment that was then compounded by a lack of staff and resources.

In this second quotation, Sammy describes feeling over-stretched looking after two critically unwell patients and having to prioritise between them. Sammy describes the pressure and stress this exerts on her because she feels morally

responsible for both patients, and yet feels she does not have the resources to care for them safely and effectively.

“Unfortunately and this kind of situation is going to happen more and more because you've got such a big pressure on beds, on ITU beds, so you need beds and sometimes when they are in charge, because they've got the pressure, they create beds and sometimes it's not appropriate because he ended up with an agitated patient with another patient, so you've got two Level 2 [high-dependency patient: guidance states one nurse can care for two level 2 patients] but this agitated patient should clearly be a Level 3 [intensive care patient: guidance requires one to one nursing] because they've got the risk of falling and when the patient is falling it's your fault because you didn't look after him properly but, you've got two patients so.... You know you've got this, it's so, so, so, stressful and it shouldn't be.” (Sammy)

In the final quotation of this section, Max describes the stress associated with trying to make moral judgements. Max discussed his doubts about whether some patients had provided truly informed consent and worried that patients didn't fully understand the risks of their procedures and associated interventions that occur in critical care. In the following quotation, Max recalls a discussion he had with a consultant about whether it was morally permissible to continue with aggressive treatments when patients are expected to have a poor quality of life. According to Max the consultant believed it was morally permissible to continue because even though the patient may not have any independence, they could see their grandchildren.

“...that sort of moral argument about whether you should be doing something or you're doing something because you can, not necessarily whether you should... whether the patient would want... because again I'm sure if you had the opportunity to ... somebody who's recently departed actually, a consultant, once said to me, '... This person wouldn't want this, this person wouldn't want to survive like this, be a burden, be in a vegetative state etc. etc. etc. but, if you can wake them up now, which unfortunately you can't, and say to them you have a chance of seeing

your grandsons for the next two years, just see them. Okay you might have nurses running around you all day long, but you could see them, what do you think they'd say then?' And yeah, it's a really tough one because it really eats away at your thoughts because I'm not sure whether I'm being an advocate for a patient or whether I'm bowing to your thoughts because you think it's morally right to do these things. And I'm sure that argument has, and that discussion has great weight, but, it's a difficult one... the whole set of morals of whether we should, shouldn't or because we can, should we? It really causes a hell of a lot of stress and having been on the receiving end of that kind of discussion without putting myself in that predicament it... yeah, even to an external it's, yeah it causes a lot of distress and on family members as well." (Max)

5.2.9 Summary of Section (i)

In this first section, I have presented my interpretation of the most commonly expressed emotions experienced by participants through the course of their clinical work. To make the process as transparent as possible I have provided my interpretations alongside verbatim quotations from participants. Differentiating between and categorising emotions in this way is problematic because emotions are complex, inter-related and highly subjective (Nussbaum, 2001). We cannot receive external verification of one another's reported experiences and so we must rely upon self-report and one's ability to identify and classify one's own, or indeed others emotions (Nussbaum, 2001). Furthermore, a substantial limitation of these findings is that the emotions and interpretations are only from within the context of Western culture. Although the participants all had varying degrees of clinical knowledge and experience, they were all from Europe and only one participant was from a minority background. It is possible that had participants been from a broader range of backgrounds that there may have been even more variation in the emotions shown.

Part of the tension of both feminist and phenomenological methods is the construction of generalities and themes from unique experiences, and therefore whilst I have constructed these groups of emotion, it is with the caveat that each of these emotions may have been experienced differently by each individual (Fisher, 2010). Nonetheless, what I have found from the findings thus far is that there is not one singular, unitary emotion that can be said to make up ‘moral distress’ but rather a variety of emotions; and this is exactly what the phenomenological method has enabled me to explore (Adams and van Manen, 2017). In telling these narratives, I have expanded upon the circumstances in which these emotions occurred and so I have already begun to construct the next themes: the moral events in which these emotions occurred. I have suggested that certain emotions seemed to be more commonly expressed during particular moral events and this is outlined in Table 12 (p.230). There is cross-over between these categories and it may be that different individuals from other cultures would experience different emotions during these moral events. Nonetheless, these categories represent the general findings from this group of nurses and the emotions identified may help others who may be able to determine the cause of their distress by identifying their predominantly felt emotions. In the next section, I will provide an analysis of the moral events during which these emotions occurred.

Table 12: Predominant Emotions during Moral Events

Moral Event	Predominant Emotions	Other Associated Emotions
Moral Constraint (internal/external)	Anger, Frustration, Powerlessness, Guilt - moral agent feels/knows/believes the right thing but feels, or is actually constrained. This may result in the perception they have committed a moral wrong.	Regret, Sadness/Upset - moral agent feels/knows/believes the right thing but feels, or is actually constrained. This may result in the perception they have committed a moral wrong.
Moral Tension	Anger, Frustration, Powerlessness, Guilt - a precursor to conflict as moral agent feels/knows/believes the right thing but feels, or is actually constrained and unable to engage in moral conflict with others. This may result in the perception they have committed a moral wrong	Regret, Sadness/Upset - a precursor to conflict as moral agent feels/knows/believes the right thing but feels, or is actually constrained and unable to engage in external moral conflict with others. This may result in the perception they have committed a moral wrong.
Moral Conflict	Anger, Frustration, Powerlessness, Sadness/Upset - moral agent engages in conflict but unable to fulfil their preferred moral requirement.	Guilt, Regret - moral agent engages in conflict but unable to fulfil their preferred moral requirement.
Moral Dilemma (initial/ residual)	Guilt, Torn, Frustration, Sadness/ Upset - moral agent may be unable to decide between two or more moral requirements; the moral agent may feel the loss of the unfulfilled moral requirement (initial) Regret, Guilt, Sadness/Upset - the moral agent may feel the loss of the unfulfilled moral requirement (residual)	Anger - moral agent may be unable to decide between two or more moral requirements (initial) ; the moral agent may feel the loss of the unfulfilled moral requirement (residual)
Moral Uncertainty (initial/residual)	Torn, Frustration, Guilt - moral agent feels conflicted and uncertain about the right thing to do (initial) Regret, Guilt - moral agent feels uncertain about whether they prioritised the correct moral requirement (residual)	Anger - moral agent may feel uncertain and unsure about the right thing to do (initial) Sadness/Upset - moral agent feels uncertain about whether they prioritised the correct moral requirement (residual)

5.3 Section (ii) Moral Events

At the centre of each participants' narrative was a moral event that seemed to serve as the catalyst for the various emotions experienced.

5.3.1 Moral Constraint

Feelings of anger, frustration, powerlessness and guilt were most commonly expressed when participants felt morally constrained. I have labelled these 'moral constraints' rather than simply 'constraints' because they prevent the agent from carrying out an action that is moral in nature, or which has moral repercussions. The constraints on participants were various and complex and as Epstein and Hamric (2009) have suggested, they seemed to be both internal and external. In the previous section, I discussed some of the constraints that caused participants to experience various negative emotions such as the hierarchy preventing participants from enacting their moral agency. However, it was often difficult to determine which constraints were internal/ perceived and which were external/actual. For example, when participants described feeling disempowered and silenced, this could be due to working in an environment or team which discouraged nurses from speaking up. It is likely therefore that internal and external constraints are interrelated.

Constraints seemed to occur when participants reported feeling they knew the right thing to do. In chapter 3, I critiqued previous definitions of moral distress on the basis that they accepted 'moral judgement' as a necessary condition for moral distress but then used different terminology to describe moral

judgements. Indeed, I am reluctant to use the term ‘moral judgement’ because although some participants seemed to articulate a feeling of certainty, others described a *‘feeling of knowing’* the right thing. Many participants said, “I feel like...” and went on to describe their moral viewpoints which, I suggest, reveals how their feelings and intuitions often guided their beliefs. In the following quotations, I present three participants discussing how they came to ‘know’.

Although Joyce was a junior nurse, unlike many other junior nurses, she articulated confidence in her judgements. In the first of three quotations, she clearly articulates her belief that the patient should not have had a tracheostomy inserted, and states ***“I don’t think”***. Joyce was angry and upset about this decision and felt that the consultant, rather than engaging in moral conflict with the family, had instead allowed them to make the decision.

“I don't think he should ever have been trach'ed [had a tracheostomy inserted] but that's what the family wanted so that's moral distress. It's like the consultant has tried to get through to them but at the end of the day they didn't say we're going to stop things, we're going to withdraw, but sometimes you do see that happen, sometimes the consultants do take that stand and that stand is needed but for whatever reason they decided not to take that approach this time around and now he's just with us waiting for a bed, he'll never go home.” (Joyce)

In the second quotation, Elizabeth articulates *feeling* like she isn’t doing the right thing and by the end of the quotation she is back to doubting everything she has just said, as she states, ***“we don’t want to write somebody off”***. Elizabeth seems to feel like she knows the right thing but she isn’t certain.

“...there’s the other side to it where you just feel like you’re not doing the right thing with those sorts of patients and I think that comes through when they are maybe older or have had really traumatic injuries...er... where beyond... you are beyond any doubt that this is going to turn out very poorly. Er, or when you get patients who have been maybe in care homes with eye tracking and really bad cognitive damage since having out of hospital cardiac arrests and you’re like I’ve seen this ten years on I know like...you really start to question whether you’re complicit in someone else’s suffering. And I do think that as a nurse sometimes you’re not really that able to like, the doctors are making a lot of clinical decisions and you’re not really able to be like, why are we doing this? What are we trying to achieve? Like are we – are we trying to achieve quantity or quality here because I think it’s quite obvious that they’re not going to achieve good quality of life but then that’s not your decision to make and that ends up being something that you do go home and just think about and think about and think about because we don’t want to write somebody off. At the same time you don’t, like you feel quite cruel, maybe cruel isn’t the right word but you know you feel complicit in – in just extending suffering.” (Elizabeth)

In the next quotation, Lily also articulates her feelings about the moral issues, and similarly to Elizabeth, she doesn’t seem to have complete confidence or certainty in her judgements.

“I do feel like sometimes, in her case especially, she got lost as a person you know in all this process and I can’t imagine how 3 months of her life like this, being in agony, being in this kind of fear. It’s kind of stayed with me and this is the point, as a nurse I feel like I don’t have enough knowledge to question when we should finish, when is the right time to say there’s nothing more we can do.” (Lily)

Participants didn’t seem certain, or were at least reluctant to express certainty about their judgements or beliefs. Instead, they described feeling constrained whilst also ‘feeling like knowing’ or ‘thinking’. This suggests that moral judgement needs to be understood in a weak sense and shouldn’t be associated with certainty.

5.3.2 Moral Uncertainty

Participants described feeling torn, conflicted, frustrated, guilty and upset because they experienced moral uncertainty. In the next quotation, Holly is responding to my question, “what do you think moral distress is?” Many participants discussed the complexities of ethical decision making and expressed the belief that because medical prognostication is uncertain, this necessarily makes moral decisions uncertain too. This caused them to feel, as Holly describes, conflicted and tormented as they struggled to navigate the ethical challenges they faced.

“Where you’re in torment and conflict because of the morality, the rightness or wrongness of a situation and it’s a, it’s a very visceral thing, actually, I feel it’s sort of, um, it’s an instinctive thing, it’s a physical reaction almost that gets you before the consciousness of it.” (Holly)

As discussed in the previous section, feelings of guilt, regret and, less frequently, anger often seemed to linger following the initial moral event. These residual feelings seemed to occur most often following moral uncertainty and moral dilemmas, as participants continued to feel conflicted about whether they had done the right thing and felt the loss of the unfulfilled moral requirement.

In the next quotation, Kayleigh reflects upon the uncertainty of clinical ethical decision-making as she begins by asserting her belief that many patients with brain injuries receive futile treatment because they are not, in her view, ever going to achieve an acceptable quality of life. However, Kayleigh also considers those patients who have made a good recovery and acknowledges that it is a ***“very grey area”***.

“I think that's what life is more about, being able to converse with people but lots of people just feel, ah a hypoxic brain injury, he's trach'd [tracheostomy] and in a bed but they're alive, our TBIs [Traumatic Brain Injury] like 'they're alive' and I'm like but are they alive? It's not what I would want out of life and I think most of the people at work would say the same thing and it's not to do with a religious decision or anything else, we've just seen that people... yes okay sometimes they may wake up to a certain aspect, people may cling on to every little think like 'but they're blinking' but that's a reflex. I don't know it's difficult, it's a very grey area.” (Kayleigh)

It is not clear from the previous quotation whether Kayleigh was experiencing distress from this uncertainty, as she seems rather matter-of-fact. For Kayleigh, this conversation seemed to serve as an ethical awakening as she realised the generalisations she was making, and became aware that individuals have different perspectives regarding acceptable quality of life. I realised that for many participants, the interviews themselves had created time and space for discussion and reflection of their experiences and beliefs. As a result of this realisation, my interview method became more Socratic as I probed the participants' emotions, moral beliefs and judgements. This mirrored the 'philosophy seminar' style of focus groups previously carried out by Alderson et al. (2002). Alderson et al. (2002) held seminars for healthcare professionals working in genetics and reported that participants felt the seminars provided an opportunity to reflect and they enjoyed the opportunity to be challenged on their assumptions and preconceived ideas. I was not challenging the validity of the participants experiences but rather in some circumstances challenging their assumptions. For some, this reflective process meant they reconsidered some of their beliefs and assumptions. Indeed, Dunn et al. (2012) argue that in empirical bioethics the researcher should not simply accept participants normative accounts but must co-construct knowledge by being critically normative. By

probing and challenging some of the participants' experiences in a non-confrontational way, participants could reflect upon their prior assumptions.

As described in the previous section, participants did not describe their negative emotional experiences as being exclusively linked to moral certainty and I have suggested that if the term 'moral judgement' is retained then it needs to be considered very loosely. Many participants expressed a lot of moral uncertainty and this caused frustration, guilt, upset, feeling torn and conflicted.

5.3.3 Moral Tension

In contrast to a moral conflict, moral tension arose when participants made some sort of moral judgement but were unwilling to articulate it and so avoided engaging in conflict. Tension seemed therefore, to be a precursor to moral conflict and tended to be experienced by junior nurses who discussed feeling unprepared to deal with morally challenging situations, often describing themselves as 'just' nurses, believing that it wasn't their place to contribute to decision-making. Junior nurses, in particular, seemed to refrain from engaging in conflict because they lacked the confidence (inner/external constraint) to manage ethical problems, and this meant they often deferred judgement to more experienced clinicians. In a review of the literature exploring nurses ethical reasoning, Goethals et al. (2010) found that often nurses had a tendency to conform to the decisions of others when faced with difficulties in ethical decision-making. This seemed to be the case when participants didn't feel comfortable or able to form or share their moral judgements. Moral tension seemed to create the same predominant emotions as conflict: anger, frustration,

guilt and sadness, and could also explain why younger and less experienced nurses in other studies reported experiencing higher levels of moral distress constraints (Corley et al., 2005; Allen et al., 2013; Woods et al., 2015).

In the next quotation, junior nurse Elizabeth expresses frustration discussing her perceived lack of ethics education which caused her to feel unprepared to engage in ethical discussion and decision-making. Elizabeth and Lily both describe feeling unable to engage in ethical discussion due to lack of knowledge.

“I have not had a course in ethics, I did not study philosophy I’m not sure if I’m equipped. And I think that’s really scary and there’s quite a lot of distress that comes out of that, it’s like I’m not sure if I’m really equipped to make these decisions or be part of the team that makes these decisions yet here. I am at the age of [early twenties] watching or helping someone to die and that - that’s your job and that’s what you do and it does seem very odd. I think that’s, I’ve kind of wondered that a lot in my career and just like I am, I – I’m you know that whole thing with nurses like you’re an angel it’s like no I’m not...I do not feel like I’ve got the sufficient like moral muscle to really like thrash this decision out like all the time.”
(Elizabeth)

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“...as a nurse I feel like I don't have enough knowledge to question when we should finish, when is the right time to say there's nothing more we can do.” (Lily)

Whereas senior nurses, such as Rachel and Phoebe seemed to describe openly engaging in conflict and questioning doctors’ decisions. In the next two quotations, they both suggest that they irritate the medical team because they are constantly questioning their decisions. However, they both still highlight that the decision remains out of their control.

"I know that I drive the doctors mad, I'm always like, "but why, but why?" and then once I get my answer I'm okay I kind of see where you're coming from or I will say "I don't agree with you, I don't agree with that, but we'll go with this plan but I want you to know that as a nurse I don't agree with it and I think the bedside nurses feel the same"." (Phoebe)

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"...and there's me rattling in there like an annoying fly. They just want to bat me away, they don't want to deal with it because I'm just another problem for them to resolve and it's a big thing because then they've got to challenge the burns doctors and there's a whole big team of them and they think they're right and I think I'm right but even though I'm voicing my opinions to everybody it's not my decision is it." (Rachel)

Despite these differences between junior and senior nurses regarding their level of confidence and engagement in ethical discussion and conflict, both junior and senior participants reported feeling they lacked ethical training, education and guidance.

GM: "...do you feel like you've had much ethics training?"

Phoebe: "No, gosh no. No, you have like a little lecture when you train and then that's it; job done. That's it, that literally is it."

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"Regarding ethics, my knowledge of ethics from nursing school, they tried to explain ethics but mainly it is trust and guidelines. They had this short explanation on what do we expect to provide for the patient and what is appropriate and things like that but not specific to critical care and end of life and what is appropriate about how to deal with that."

(Lily)

Possibly consistent with their lack of formal ethics education, senior nurses seemed to draw upon previous experiences to guide their decision-making, and this gave them confidence to engage in conflict. In the next quotation, Olivia states her belief that she has only ever made one error in judgement regarding whether life-sustaining treatment ought to be considered futile and withdrawn.

“... I still think even though that one time I got it wrong that I know about, I'm still quite vocal with saying no we should withdraw care on this one. ... I think the Neurosurgical patients in the young ones we're too... we need to give them a better chance rather than saying no withdraw care but when you've got a 91 year old that comes in who's fallen on the stairs with fixed, dilated pupils, why are we going to ventilate them and give them... medically manage them for two days and see where we get to, what are we trying to achieve when they're in their 90's, they're not going to... I don't know what we're trying to achieve to get these people better.”
(Olivia)

I found myself questioning Olivia's judgement at this point because she seemed to show a lack of awareness for the complexities regarding decision-making. This raises questions regarding whether senior nurses' judgements are robust. Making moral judgements using past experiences doesn't account for differences between patients and therefore may result in flawed decisions. Johnstone and Hutchinson (2015), reporting on a study by Ham (2004), found that “the more years of experience the nurse participants had, the less inclined they were to use a critically reflective approach to their ethical decision-making in practice, instead relying on their own personal values.”(p.9). Junior nurse Elizabeth seemed to show more of an awareness of the complexities of ethical decision-making than Olivia.

5.3.4 Moral Conflict

To avoid the conceptual confusion discussed in chapter 3, I will clarify the way moral conflicts and moral dilemmas are interpreted in this study, and this is different to Jameton's interpretation. Whilst Jameton (1984, 1993) seemed to accept a 'common-sense' definition of moral dilemmas in which they are akin to a moral conflict (one is faced with a difficult moral decision but with enough thought one is able to identify the morally correct course of action), the position

I will take in this thesis is one, taken from Tessman (2015, 2017) that posits moral conflicts and moral dilemmas as similar but distinctly different phenomena. Tessman's position is adopted as the underpinning theory because participants seemed to experience the phenomena in ways reflective of Tessman's distinction.

Moral conflicts are defined as:

“A situation in which:

1. there is a moral requirement to do A and a moral requirement to do B;
and
2. one cannot do both A and B.” (Tessman, 2017, p.27)

In moral conflicts, participants described feeling angry and frustrated because they could not carry out the moral requirement they believed was required. In contrast to moral tension, conflicts seemed to be more public and active as participants felt they knew which moral requirement should be fulfilled. Participants described engaging in moral conflict with nursing colleagues, patients, families, and most frequently with medics. In these situations, participants felt they knew the right thing to do but perceived fundamental differences in opinions and values between themselves and the doctors. In the following quotation, senior nurse Rachel discussed the frequent conflicts she engaged in with doctors regarding end-of-life care. Rachel describes frequently questioning their rationale for treatment decisions and appeared to be frustrated and angry by what she perceived as their lack of forethought.

“...with lots of situations there are patients that you just think, what are we doing? what are we doing; we're torturing this poor patient, it's time to stop and let them die and I have had that conversation so many times with the doctors to say, 'what's your plan; you're really going to do that to them? You can't, they've been through... and is that going to resolve anything?' And because it is their decision, and it depends on how involved they are or whether they're just covering for a shift or whatever whether they'll just say, 'no we'll carry on and we'll carry on'...” (Rachel)

Powerlessness further complicated participants experiences of moral conflicts. Due to participants' position within the decision-making hierarchy they were almost always additionally constrained during a moral conflict. This might explain why many researchers suggest that moral constraint is a necessary part of moral distress. Whereas, other researchers have argued that moral distress occurs due to a broader range of experiences, such as during moral conflicts (Fourie, 2015).

Moral conflicts could be distinguished from dilemmas because although they could cause sadness, guilt and regret, these emotions did not have the same lasting and residual effects that occurred during dilemmas (see section 5.3.5). For example, in the next quotation Elizabeth states, ***“I've never been in a situation where I don't feel like we haven't made the right decision”***. This suggests that although the decision was frustrating, difficult and distressing, as Elizabeth perceived it, the moral requirement to continue life-sustaining treatment vs. withdraw life-sustaining treatment were negotiable in light of the prognostic uncertainty and therefore the cost was one that could be borne and the right thing happened.

“So, I think the distress comes from that rock and a hard place and that’s definitely the crux of it, it’s like I don’t feel comfortable standing here and it’s been months and month and months and just I feel like I’m dragging out this family’s pain and I may be dragging out your pain to like what end... and why are we doing this? And this doesn’t seem right and this doesn’t seem fair or nice. But on the other side you’ve got what feels like sometimes a little bit of a like educated guess... those are the ones that pop up in the night you know those are the faces where you’re just a bit like.... I think a lot of the time, I’ve never been in a situation where I don’t feel like we haven’t made the right choice but I’ve definitely, definitely been in the situation where I’ve spent a lot of time questioning it and yeah it’s that rock and a hard place, it’s that gamble on someone else’s existence, well it is, you’re gambling on their existence and what state that existence will be.” (Elizabeth)

5.3.5 Moral Dilemma

Whilst moral conflicts seemed to be characterised by frustration, anger and powerlessness as participants described the negative emotions associated with trying to choose between moral requirements; moral dilemmas seemed to have more of an enduring and lasting nature such that feelings of guilt and regret characterised their presence. In the next quotation, Isabelle describes an experience first described in section 5.2.4. She seemed to be torn and conflicted between her duties to the patient and the patient’s family, and after trying to advocate on behalf of the patient who seemed to be articulating a preference for palliative care she came into conflict with the patient’s partner. Isabelle describes her residual guilt and regret about whether she did the right thing, articulating a feeling of moral remainder.

“...you know, did I misunderstand, did we all misunderstand this? What is the right thing to do? What’s my job? Is it to look after her, or the family, or both? And in that case what do I do when both interests seem to be different? Yeah, I think that was the main thing, just and if it was the right thing why does it feel so hard and so painful, because often if you do the right thing you go home satisfied thinking I have done what I am supposed to do...” (Isabelle)

Tessman (2015) defines moral dilemmas as:

“a situation in which there is a moral requirement to do [or to refrain from] A and a moral requirement to do [or to refrain from] B, where one cannot both do [or refrain from] A and do [or refrain from] B, and where neither moral requirement ceases to be a moral requirement just because it conflicts with another moral requirement, even if for the purpose of action-guidance it is overridden. In a dilemma, whichever action one chooses to perform [or refrain from], one violates what has become, through one’s choice, the impossible moral requirement to do [or refrain from] the other action.” (Tessman, 2015, p.15).²⁴

As Tessman (2017) explains, in conflicts one can “for the purpose of determining what you ought to actually do, take one of the moral requirements to override the other one” (Tessman, 2017, p.28). The moral requirements in a moral conflict can be successfully negotiated such that one can be taken to override the other without a moral remainder because it is a negotiable moral requirement. Whereas the moral requirement in a dilemma is non-negotiable,

²⁴ Both Tessman’s work and this thesis are feminist works grounded in an investigation of how non-rational actors navigate morality in a non-ideal world, therefore the word “requirement” is taken broadly to refer to a plurality of values allowing that what one person may hold to be a non-negotiable moral requirement, another might not, and therefore moral dilemmas are perceived and experienced uniquely by different individuals. What I experience as dilemmatic, you might not because of the different values we hold.

and so although the moral agent may choose (for the purpose of action guidance) to fulfil one moral requirement instead of the other, this does not mean that it ceases to be, because it cannot be substituted.

Looking back at Isabelle's experience, she seemed to be suggesting that by carrying out one moral requirement (to act according to the families wishes and their interpretation of best interests), the other moral requirement (to act in the best interests of the patient) was not successfully overridden and the patient was forced to bear a cost that no one should have to bear. This caused Isabelle to experience the initial and residual feelings of guilt, anger and regret that are associated with moral dilemmas.

To determine whether a moral requirement is negotiable or non-negotiable, Tessman (2017) draws upon the work of Nussbaum, and her capabilities approach. Nussbaum (2000) suggests there are ten capabilities that are required as a "matter of basic minimum justice" (p.1020). One of which is life: "Being able to live to live to the end of a human life of normal length: not dying prematurely, or before one's life is so reduced as to be not worth living" (p.1021). When a non-negotiable moral requirement is violated it creates a loss that cannot be compensated for and imposes "costs that consist in being made to bear a burden that no citizen should have to bear" (p.1019). Tessman (2017) also employs Williams (1965, 1973) phenomenological argument (discussed in section (i) of this chapter) that moral conflicts can be distinguished from dilemmas because dilemmas leave a moral remainder or moral residue.

Therefore, according to Tessman (2015, 2017), there are three main characteristics that distinguish a moral dilemma from a moral conflict:

1. The moral requirements, or values involved are non-negotiable and therefore cannot be substituted.
2. The violation of a non-negotiable moral requirement leaves a moral remainder/moral residue.
3. Because the lost value cannot be compensated for it results in a cost that “no one should have to bear” (Tessman, 2017, p.59).

In the next quotation, Beth seems to express the feeling that she carried out an action that entailed costs that no one should have to bear but given the constraints on her moral agency, she was left with no other option than to violate a non-negotiable moral requirement. Again, the presence of moral constraint further complicates the moral event as Beth did not have freedom of action to choose between A or B. Nonetheless, Beth seems to suggest that despite fulfilling one moral requirement (to maintain what she perceived as a worthy life), the other was not substituted (prevent suffering and pain/ respect autonomy). Beth discusses the guilt she experienced both during the initial event and which lingered afterwards. This suggests that, like many participants discussed in section (i), her feelings of guilt signalled moral residue/remainder which is the mark of a moral dilemma.

“I have to do it and I know that I have listened to her and I am telling her, ‘We have heard you, we are hearing you, we are doing everything we can to get this process going, underway, we are doing this, we are doing that, we are doing this, so it’s not that I am not listening to you but we have to

do this right and in the meantime, I need to look after you.’ But she still didn’t want me to. So, it was the guilt that I felt like I was hurting her, even though I knew we were right in the process of what we were doing and it had to be done that way but when I am standing right in front of her and doing these things with her... I could see her distress and that she was so upset and it just made me feel guilty. No matter how right I knew I was on a practical level, you know, seeing how it made her feel, it just, made me feel guilty.” (Beth)

To summarise, moral dilemmas seemed to cause similar emotions to moral conflicts but they also left residual feelings of regret, guilt, sadness and sometimes anger. These initial and residual feelings seem to signal the feeling of having violated a non-negotiable moral requirement.

5.3.6 Moral Failure

There was also a sense to which participants’ narratives of moral dilemmas felt tragic. In the next quotation, Grace reflects upon what could have mitigated her moral distress experience and suggests there is a sense to which failure feels inevitable; no matter how a moral problem is managed, you can still feel you have failed. Phoebe discusses how difficult ethical decisions need to be made in critical care and they will always feel difficult.

“...with the kind of stuff that is morally distressing, I, I don’t think any amount of teaching or preparation will actually stop – it certainly wouldn’t stop me feeling morally distressed about certain things but I think, you know, if there is something that happens erm, it can be really useful to talk about it with the people who are involved and erm... because it is a bit of a relief when you realise that people feel the same as you. You feel like you’re not kind of carrying the whole world on your shoulders.”
(Grace)

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“It’s a tricky one because there are lots of ethical issues in that you’re making a decision about somebody else’s life but at the same time somebody has to make that decision because that’s part of Intensive Care, that just has to happen.” (Phoebe)

Again, Tessman's work helps to clarify the participants' experiences. Tessman (2015) suggests that when one is faced with a moral dilemma in which non-negotiable moral requirements conflict, they face unavoidable moral failure. Due to the nature of critical care, the complexity of ethical decision-making and the moral requirement to continue carrying out one's professional responsibilities, participants seemed to feel doomed to moral failure and therefore doomed to feel the negative emotions associated with moral distress.

5.3.7 Summary of Section (ii)

Earlier, I discussed the emotions described and expressed by participants and the situations in which they occurred. These negative emotions fall under the umbrella emotional state of 'distress'. In this section, I further explicated the situations in which these emotions occurred. Table 12 summarises the predominant emotions that seemed to be experienced with each moral event, and the following is a summary of each moral event:

1. Constraint - the moral agent may feel/know/believe which moral requirement to fulfil (for the purpose of action-guidance) but is unable to carry out their preferred moral requirement due to (perceived or real) external or internal constraint. There is no moral residue.
2. Conflict - the moral agent may feel/know/believe (for the purpose of action-guidance) which moral requirement to fulfil, substituting one for another. The moral agent may be prevented from enacting/fulfilling their moral agency because of a constraint. There is no moral residue.

3. Tension – the moral agent may feel/know/believe (for the purpose of action-guidance) which moral requirement to fulfil but is/feels constrained and therefore refrains from engaging in actual conflict. The moral agent may believe they have committed a moral wrong. There is no moral residue.
4. Dilemma - the moral agent is unable to decide/ is unable to fulfil two or more non-negotiable moral requirements that cannot be substituted. There is moral residue.
5. Uncertainty - the moral agent is uncertain/ unable to decide which moral requirement to fulfil – if the moral requirement is non-negotiable then they may experience moral residue.

The narratives within this dataset suggest certain emotions may be more commonly associated with particular moral events and so by identifying one's predominant emotions this could help individuals to identify the underlying moral event and possibly the best way to respond. For example, if the moral agent is feeling torn, this may indicate they are experiencing moral uncertainty or a moral dilemma and one way to respond would be to provide the moral agent with moral guidance so they can discuss their ethical concerns and try to reach an ethically-justified conclusion. However, before I go on to discuss possible responses to moral distress, I will first explore the causal relationship between the moral event and the various emotions experienced by participants.

5.4 Section (iii) Causal Relationship

Within this final section, I will highlight how the themes of space, proximity and personal/professional responsibility in combination with a piece of tort law can explain the causal relationship that is required between a moral event and the umbrella emotions of ‘distress’ to label an experience one of ‘moral distress’.

5.4.1 The ‘Alcock Criteria’ as a Causal Story

To tell this causal story, I am drawing upon a set of criteria drawn from tort law in *Alcock v Chief Constable of South Yorkshire Police* [1992] 1 AC 310. The ‘Alcock Criteria’ is a set of criteria that arose following the Hillsborough disaster which occurred in 1989 in a football stadium in Sheffield. There was overcrowding in the stadium and 96 football fans were crushed and died. Some of the relatives of the primary victims sought to claim negligence as secondary victims because they claimed they had suffered a psychiatric illness following the disaster. To prove they were secondary victims, and to bring a successful claim, the following 5 criteria needed to be established:

1. Close tie of love and affection with a person killed, injured or imperiled.
2. Claimant close to the incident in time and space.
3. Claimant directly perceived the incident, rather than via a third party.
4. Illness was induced by witnessing the sudden shocking event.

5. The illness suffered is a recognised psychiatric injury or illness.

There is existing literature suggesting healthcare professionals can be secondary victims, and the term is believed to have been introduced to the medical literature by Wu in 2000 (Tamburri, 2017). In this literature, nurses are said to suffer physically, emotionally, professionally and psychologically due to their involvement in adverse events and there are calls for the creation of healthier work environments that support secondary victims (Tamburri, 2017). I do not wish to claim that nurses experiencing moral distress are secondary victims but rather that the causal requirements in the Alcock criteria, with some amendments, may help us to think about and characterise the causal relationship required between participants' emotional responses and the moral events that putatively triggered them. The causal criteria may also help to explain why some individuals experience moral distress whilst others do not. I suggest amending the Alcock Criteria as follows:

1. There is a feeling of either: other-regarding or self-directed empathy for the individual(s) involved in the moral event;
and/or recognition and acceptance of a feeling of personal/professional responsibility to those involved in the moral event, including towards oneself.
2. The nurse has a proximate relationship to the moral event in time and space.
3. The nurse experiences a combination of emotions that may be regarded as falling within the umbrella emotion 'distress' following involvement in the moral event.

The third criterion has already been explicated in the previous two sections. Criteria 1 and 2 are supported in the data in the following ways:

5.4.2 Empathy

In the ‘Alcock criteria’, it was determined that to be a secondary victim one must have a close tie of love and affection with the individual killed/injured/imperiled. This criterion, along with the criterion of proximity, was put in place to differentiate between close family members of victims and bystanders who had witnessed scenes of the disaster on television (Hewitt, 2015). The criteria for moral distress does not need to be as stringent because I am not trying to determine financial compensation but rather I am trying to meaningfully determine whether an individual can be said to be experiencing ‘moral distress’. Within this amended criterion, I suggest there should be a tie that connects the nurse to those involved in the moral event, and the data seems to suggest that this connection is typically either an emotional or a professional connection. I will discuss the emotional aspect in this section.

In section 5.2.5, I discussed the upset and sadness that participants seemed to experience following moral events. These feelings led some participants to attempt to mitigate their emotional responses by detaching themselves and distancing themselves from suffering. Beth describes adopting a “*practical*” and “*logical*” position in order to make clinical-ethical decisions. Many participants discussed feeling emotionally invested in patient care and outcomes, and they perceived this as having a negative effect on their own

mental wellbeing. Beth described feeling “*wrapped up*” in others’ emotions which she found “*difficult*” and “*draining*”.

The feelings of emotional investment and attachment described by participants seemed to imply that feelings of empathy connected them to those involved in moral events. Sinclair et al. (2017a) discuss how empathy is thought to have both a cognitive and an affective element. The cognitive element is characterised as “detached acknowledgment and understanding of a distressing situation based on a sense of duty” (Sinclair et al., 2017a, p.438) and could overlap with feelings of professional responsibility that I will discuss in the next section. Whilst affective empathy “extends to an acknowledgment and understanding of a person’s situation by ‘feeling with’ the person” (Sinclair et al., 2017a, p.438). Indeed, this seemed to be the way that many participants characterised their responses to patients. Participants discussed grieving for patients, continuing to think about them after work and coming in early to check on their progress. These feelings seemed to go beyond the bounds of professional caring and became a ‘feeling with’. In the next quotation, Isabelle describes the grief and guilt she felt following the moral event (moral dilemma). Logically she seemed to feel like she had done the right thing, but she continued to feel guilty, and her feelings of empathy seemed to connect her to the moral event.

“I’m sort of covering it but you know it’s painful. Now I know it was the right thing to do but it’s never going to leave me and I have thought about her and she was more than a patient. In many ways, I wish I could have seen... I really wanted to go to the funeral to talk to him and say, well just apologise if it wasn’t the right way or I don’t know, they didn’t invite us...” (Isabelle)

Other patients explicitly mentioned empathy. In the following quotation, Beth discusses a moral event she experienced (first discussed in section 5.2.3) and the feelings of guilt and regret this event caused her. She describes how she felt empathy for the patient and family as they tried to decide whether withdrawing life-sustaining treatment was the right thing to do. In the second quotation, Grace discusses the importance of empathy, suggesting that it is vital for nurses to be empathetic.

“...it started to become something that you know we talked about as colleagues because I think everyone felt it. Felt this human empathy for her, that is was a horrible situation for anyone to be in but knowing that she was being so persistent about this message that she didn’t want this anymore. And everyone felt it, that they wanted to do their best to look after her but knew she wasn’t happy.” (Beth)

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“...so much about being a nurse, I think, is about having empathy. Like I think you have to be really empathetic towards your patients but, at the same time, you have to sometimes realise that sometimes, you just, you just don’t know; like you – because you’ve not had that experience or... how they’re feeling and I couldn’t put myself in that man’s shoes.” (Grace)

The importance of empathy was also highlighted through participants’ discussions about how they didn’t want to be. For example, Elizabeth describes how in some ways she perceived moral distress as positive because it showed she still cared deeply enough for patients to become distressed. Grace discusses working with nurses she perceived as uncaring and talks about the fact she never wants to be that way.

“...it shows that you care on a level I mean yeah I would say that especially with ...yeah because you’re distressed because your don’t feel 100% confident in something that has happened, if you didn’t feel distressed because you didn’t care then you’d just be rubbish like, you’d

be terrible, you'd be like oh well nothing could have been done."

(Elizabeth)

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"Well with her I think she had just been doing the job for too long and didn't like it. She didn't want to be doing it anymore so got to the point where she just didn't want to be there. I think to be honest if I ever got to that point I won't be there anymore. I would move on. I don't want to end up with that kind of approach. I think to an extent having some sort of I suppose empathy for your patients is going to make a big difference as well and it's the difference between explaining to someone this is why you need to do something or just saying to them this is what we're doing. For the most part the people I run in to seem to be quite human." (Rebecca)

Some participants framed empathy as similar to compassion and sympathy. For example, in the next quotation, Chloe discusses her belief that they are essentially the same thing:

"I wouldn't say sympathy and compassion are separate. I think caring for somebody is showing them compassion, but at the same time you also have to sympathise with the fact that you've got to care for them because they can't do it for themselves. So to me in my head they're the same, erm, I would never let my – the way I feel about it interfere with the level of care I gave to a patient. Erm, and in my head all of that is patient care, sympathy, empathy, compassion, all of it is..." (Chloe)

However, I disagree with Chloe. There are important differences between sympathy, compassion and empathy. There is a lot of literature regarding compassion and empathy, and to a lesser extent sympathy. To articulate the differences without getting caught up in this conceptual literature, I am instead going to rely on the dictionary definition to highlight the differences. According to the Oxford Living Dictionary:

Sympathy: “Feelings of pity and sorrow for someone else’s misfortune.”

(Oxford Living Dictionary, 2018a)

Compassion: “Sympathetic pity and concern for the sufferings or misfortunes of others.”(Oxford Living Dictionary, 2018b)

Empathy: “The ability to understand and share the feelings of another.”

(Oxford Living Dictionary, 2018a)

These definitions mirror those suggested by palliative care patients ($n=53$; adult patients with a terminal cancer diagnosis and life-expectancy of less than six months) in a recent grounded theory study by Sinclair et al. (2017a). Sinclair et al. (2017a) reported that patients perceived sympathy as pity-based and was therefore largely unwanted, whereas compassion was viewed as virtuous because it was associated with the desire to address suffering, and empathy was seen as an attempt to understand another’s suffering, develop a personal connection and deeper understanding. These characteristics are key to empathy’s causal role for the concept of moral distress as it is an important other-regarding emotion which seems to connect nurses to patient suffering. In the absence of empathy and or a professional connection, it is difficult to imagine how an individual would feel distressed about a moral event. The role of empathy within the causal chain also helps us to understand why some authors have suggested that experiencing moral distress may not necessarily be bad. For example, Nyholm (2016) suggests that being of the disposition to

experience moral distress may be seen as a virtue because it shows that one takes ethical concerns seriously; moral distress can be “morally good in being an appropriate response to a troubling situation” (p.19). Nyholm (2016) does not suggest that we should welcome moral distress or that we should not provide support for those experiencing moral distress, but rather that we should recognise that it does have some value.

The understanding of empathy that I suggest is a relational understanding of empathy from Campelia (2017). Campelia (2017) also stresses the cognitive and affective aspect of empathy, and argues that empathy is a relational practice that requires the individual to engage with whom they are empathising with, whether through for example, touching, asking, discussing, reflecting and so forth. Relational practice is central to the nursing role and is potentially intensified in ICU where one nurse cares for one patient for the entire day. As Amelia describes in the next quotation, she feels she is that patients dedicated ‘person’, learning all about them and devoting her day to them.

“my experience on ICU, with one patient normally, where you devote your entire day to them and you know everything about them, it just really appealed to me. I just love the idea of this one person and their outcome is your focus, and their ‘your person’, and you’re ‘their person’.” (Amelia)

Furthermore, Campelia (2017) argues that empathy is an epistemic practice capable of generating reliable knowledge that has real utility within a social epistemology. If it is accepted that empathy has a causal role to play in moral

distress, and that it has epistemic value, this may also emphasise the value of moral distress as a phenomenon that can alert us to moral problems.

There were also situations in which participants seemed to feel distressed because of their own circumstances within a moral event, feeling for example, that they had been morally wronged. In these circumstances, I suggest that the causal chain goes the other way. The nurse experiencing moral distress is involved in the moral event and the empathy is either self-directed or they feel that personal or professional responsibility was owed to them. Dudzinski (2016) argues that moral distress is always related to patient well-being, but this did not seem to be the case for these participants who also seemed to feel distressed when they felt morally wronged. An example of this could be nurses who feel moral distress because they are the victim of epistemic injustice (which I discuss in the next chapter).

Empathy is not therefore necessary to fulfill this first causal criteria because the individual could instead recognise and accept the feeling that personal/professional responsibility is owed to oneself or others. However, it does seem that feelings of empathy intensified the causal relationship and I suggest that nurses more skilled at empathy may be more likely to experience moral distress. Additionally, this causal connection explains why some participants reported trying to distance and harden themselves in response to moral distress experiences.

5.4.3 Responsibility

Nurses may not necessarily feel empathetic or emotionally connected to those involved in moral events, but still experience moral distress. I suggest that in these circumstances, it is because they either feel a sense of personal responsibility (which seems to have cross-over with feelings of empathy because participants discussed connecting to patients on a human level), or they recognise and accept a sense of professional responsibility. Again, this emerged from participants' narratives and seemed to contribute to the causal story because the feeling of responsibility connected the individual experiencing distress to the moral event. When responsibilities conflicted, this seemed to constitute a moral event in itself and the feeling of self-empathy created distress. I discuss this in chapter 6.

In the next quotation, Beth frames her feeling of professional and personal responsibility in terms of advocacy. She describes how nurses are assigned the responsibility of patient advocate, and this connects them to the patient in a unique way.

“The final decision's not on me, I know that, but I'm part of it and I've got a big responsibility on their behalf I guess, nurses are an advocate for the patient, that is really what we are promoted as aren't we so, you know, having that kind of personal connection with this patient and with the previous one, having this kind of very open communication and talking to me, and then knowing I bear responsibility for trying to help them...sensibly and appropriately help them to get the kind of care and treatment that they want...but sometimes it not always turning out the way that they want. I think that is kind of the root of it, you know, because I think when you're, anyone, when you're trying to do the best job you can you do take it on board because you know it's your responsibility” (Beth)

Beth appeared to recognise and accept her responsibility as the patient's advocate, and this connected her to the patient and family involved in the moral event. If Beth didn't feel either a sense of responsibility or a feeling of empathy towards those involved in the moral event, then it seems unlikely she would have experienced these emotions.

Many participants reported feeling both professional and personal responsibility. In the next quotation, Phoebe suggests that variability regarding how, and to what extent, individuals feel connected to patients and families affects their moral distress experience. Individuals that are able to disconnect and create distance between themselves and the patient potentially experience moral distress to a lesser extent.

“Some people can say well I just don't think about it, that isn't something that I would ever... that's just not how my brain works, so I think it would be interesting to know what people with a different personality type and with different feelings about moral distress and that would think, if they do genuinely are just able to switch off. So I think it's something that's a very individual thing I guess is what I'm trying to say.” (Phoebe)

The importance of moral responsibility has been highlighted by other authors. For example, Gorin (2016) suggests that Campbell et al.'s (2016) broad definition should stipulate a feeling of moral responsibility between the individual experiencing moral distress and the morally-desirable situation. Both Gorin (2016) and Dudzinski (2016) suggest that moral responsibility helps us to distinguish between moral distress and distress *simpliciter*. Dudzinski (2016) suggests that moral distress is accompanied by a heightened feeling of moral responsibility and often the feeling that responsibilities are conflicting.

5.4.4 Proximity

Participants discussed the intimate connections they formed with patients and families because they shared emotional experiences with them, and because they spent so much of their time at the bed-space. As mentioned in section i, participants discussed how this proximity caused them to feel *“wrapped up”* in patients and families’ experiences, and they struggled to find emotional distance. This suggests that proximity to a moral event is required for individuals to experience a distressing emotional response, and indeed many participants discussed how sustained proximity heightened their emotional distress. For example, in the next quotation, Beth discusses her belief that bedside nurses can be more susceptible to emotional distress because of their proximity to patients. Beth suggests that proximity makes it difficult to think in a *“practical”* and *“logical”* way. In the second quote, Jenna discusses feeling *“trapped”* in a side room, unable to get the doctor to review a patient that she thought might be dying but was still receiving life-sustaining treatment.

“I think when you’re at the bedside for someone, and I guess nurses say this quite a lot. When you’re the person that’s there with them for twelve and a half, thirteen hours a day, it’s very difficult not, and you maybe shouldn’t, but it’s difficult not to get wrapped up in how they feel. Visiting teams, though I’m very sure they were doing their very best for her. I don’t think they kind of succumb to that the way we would because you’re feeling the full force of someone’s distress...all day. You’re feeling the full force of their family’s distress for most of the day so it’s really hard to kind of take that step back and be more practical or more logical in your thinking” (Beth)

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“I just wanted to cry with the daughter and be like no I think you're right but also I felt really trapped because physically I was in that side room and I couldn't have anyone to be like 'look come and look at him he's dying; let's stop this now...'” (Jenna)

The suggestion that proximity has a role to play in the conception of moral distress has also been mentioned by Peter and Liaschenko (2004) who theorised that proximity to the patient seems to compel nurses to experience their moral responsibilities most acutely; whilst other healthcare professionals are able to walk away, the bedside nurses remains in place, bearing the burden of moral responsibility. This seems to be supported in the findings, as participants frequently discussed the difficulty of sustained proximity to patients experiencing pain and suffering.

To summarise, for an individual's feelings of psychological distress to be regarded as 'moral distress', there needs to be a proximate relationship established between the individual and the moral event, thus fulfilling criteria 2 of the 'Causal Criteria':

2. The nurse has a proximate relationship to the moral event in time and space.

Moral dilemmas and moral uncertainty also seemed to cause residual feelings of guilt, regret and anger which suggests that moral residue may be a type of moral distress that extends beyond this initial causal pathway.

By establishing these casual criteria, we can rule out instances of *distress simpliciter* as moral distress. This is not to dismiss other kinds of distress but, rather, allows us to distinguish between them and enables us to establish mechanisms to respond to the different experiences. If there is no discernible moral catalyst, then it is likely the individual needs psychological support.

However, if there is a moral catalyst, there needs to be suitable support available and therefore knowing the type of moral event can help us to tailor our responses.

5.4.5 Summary of Section (iii)

In this final section, I have amended the ‘Alcock Criteria’ to develop a ‘Causal Criteria’ to explain the causal relationship between the moral event and the feelings of distress articulated by participants in this study.

Returning to the definition of moral distress that I suggested at the end of chapter 3, the following clarifications are added:

Moral distress is the combination of:

- (i) the experience of a moral event

The moral event could be any of the following: moral tension, moral conflict, moral dilemma, moral uncertainty or moral constraint.

- (ii) the experience of ‘psychological distress’

The term ‘psychological distress’ is an umbrella term that captures a variety of different negative emotions that may be expressed differently by each individual, but will often include anger, frustration, guilt, regret, sadness/upset, powerlessness, symptoms associated with stress and feeling torn.

and

- (iii) a direct causal relation between (i) and (ii)

This causal relationship may be explained using the following 'Causal Criteria':

- 1. There is a feeling of either: other-regarding or self-directed empathy for the individual(s) involved in the moral event; and/or recognition and acceptance of a feeling of personal/professional responsibility to those involved in the moral event, including towards oneself.*
- 2. The nurse has a proximate relationship to the moral event in time and space.*
- 3. The nurse experiences a combination of emotions that may be regarded as falling within the umbrella emotion 'distress' following involvement in the moral event.*

CHAPTER 6: EMPIRICAL FINDINGS: Compounding Factors

6.1 Overview

In the previous chapter, I provided my interpretation of the empirical data that were used to inform the concept of moral distress. I suggested that there are three key components of moral distress: a moral event, psychological distress and a causal relationship between them. However, a number of other themes emerged from the data as participants discussed many issues that impacted their experiences of moral distress. Within this chapter, I explore these additional factors that I have labelled ‘compounding factors’. These compounding factors seemed capable of exacerbating, and therefore potentially mitigating, participant’s experiences of moral events. At times, these factors also seemed to provide the catalyst that created the moral events in the first place. Some of these compounding factors seemed to be avoidable, for example poor communication, whilst others, such as the need to provide end-of-life care, were unavoidable. I suggest that identifying the (un)avoidable compounding factors may help us to shape our responses to moral distress.

6.2 Knowledge and Power

Decisions are frequently made in healthcare, many of which have clinical and ethical implications and therefore require clinical, moral and legal knowledge, for example, whether to withdraw life-sustaining treatment. The need to make these important decisions is unavoidable. However, the way these decisions are made can influence the nature of the moral event and whether it creates moral distress for those involved. In the next section, I discuss participants’ perception

of clinical-ethical decision-making and the effect decision-making had on their experiences of moral distress.

Participants described working in environments in which knowledge equated to power, and they described how this impacted decision-making during moral events. Consultants were perceived to be the most knowledgeable based upon their level of medical experience and training and therefore they were responsible for making important decisions regarding patient care, such as whether to withdraw life-sustaining treatment. The need to assign responsibility based on knowledge and expertise created a hierarchy, with the most knowledgeable at the top and the least knowledgeable at the bottom. Participants described feeling they were often excluded from decision-making and this seemed to exacerbate the negative emotions they experienced during moral events.

6.2.1 'Just' a Nurse

Junior nurse Natasha suggests her lack of physiological knowledge rightfully excludes her from decision-making, and seemed to believe that because nurses' knowledge and skills do not match consultants, their opinions could be justifiably disregarded.

“Well it's more like, I don't understand how every cell works in the body, I don't have that physiology background, I have some experience but it's nowhere near as much as the consultant so if they tell me something and that they are doing something for a certain reason like I haven't really got a reason to question that. I'll go away and read about it and hope that I can learn more about it but I won't necessarily be like well actually this is what it is and you should listen to me because I'm the nurse.” (Natasha)

Some participants seemed to be accepting of the decision-making hierarchy and didn't seem to feel angry or frustrated when excluded from decision-making because they perceived themselves as 'just' nurses. Acceptance of the hierarchy seemed therefore to reduce the extent to which participants felt moral distress during moral events because they didn't think they should be included. However, these participants also seemed to lack awareness of the difference between medical and ethical decisions, and assumed those with the most medical knowledge should be responsible for all decisions.

6.2.2 Specialist holistic knowledge

Not all participants were accepting of the decision-making hierarchy, and recognised a difference between medical and clinical-ethical decisions. These participants described feeling angry and frustrated when they were excluded from decision-making. They discussed the belief that although their knowledge was different to consultants, it still had value for clinical-ethical decision-making. For example, in the quotation below, Isabelle describes the realisation that her knowledge was as valuable as the consultants' medical knowledge because she understood the contextual issues. In the second quotation, Kayleigh also seems to recognise the value of her knowledge, as she knows the patient's values, wishes and desires.

“For a long time, I think up until that situation I thought it was the doctors', the consultant's but it made me realise that actually some of them have no idea what is going on, depending on who they are, like no offence to them, I do have a lot of respect for their work, their knowledge. But actually if you know the patient and the family you are in just as good if not a better position to say...like obviously the medical understanding, that's down to them, like sometimes there are things you don't grasp in the picture and I think that's why everybody was so cautious to say that's enough because you're thinking maybe I just don't quite grasp this and that but, actually knowing the patient and the family and if you have

looked after people a couple of times then often you actually have a fairly good understanding of what's going on and you can understand. But that's not really written down on paper and that's not really, like it's never a nurse decision, like a nurse responsibility to go and have a discussion with the family..." (Isabelle)

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"...we know the ins and outs of what their family would want for them, we ask those questions, we talk to them and they talk to us about what that person would have wanted and what that person was like before and how they used to live their life so I think we can probably understand whether or not they would want this." (Kayleigh)

This different type of knowledge that nurses described, I have labelled 'specialist holistic knowledge'. Participants described their intimate knowledge of patients likes, dislikes, their relationships with their family and family dynamics. Some participants saw the value of this knowledge for clinical-ethical decision-making, and those that did seemed to become more frustrated when they felt excluded from decision-making and this exacerbated their moral distress experiences. Whereas other participants, although they recognised their knowledge was different, didn't necessarily see its value for clinical-ethical decision-making. They seemed therefore more accepting of the decision-making hierarchy and this mitigated their moral distress experiences. In the next quotation, Max describes this knowledge as knowledge of the "fluffy" stuff, by which he seems to mean the patients' wishes and desires, and he downplays the value of this knowledge in comparison to empirical data.

"...we're there for 12.5 hours and we actually see and we see the very subtle changes in patients because you're there so long but you also get a picture of what the individual is like from speaking to their family as well. I think consultants base their decisions on all the statistics and stuff based around the outcomes of their treatment and the potential quality of life this patient's going to have. We tend to see the fluffy side of things as well by talking to their family and knowing what the person is like and what their wants and desires are and a feeling as to whether or not this treatment is actually working." (Max)

6.2.3 Medical Expertise vs. Ethical Understanding (Facts vs. Values)

The preceding two compounding factors raise important questions about the value placed on different types of knowledge and how this impacts clinical ethical decision-making. Most participants appreciated that consultants had medical and prognostic expertise but they articulated a tension in this, because it didn't then necessarily follow that they would make the 'right' decisions. Participants that articulated this tension also described feeling more frustrated, angry, powerless and ultimately seemed more morally distressed because they believed that ethical understanding was also required for clinical-ethical decision-making. Joyce expresses this in the next quotation as she states that although ICU consultants are experts in ICU, she questions whether this extends to palliative care.

“...you have to do what the consultant tells you, they are the experts in intensive care but are they experts in palliative care?” (Joyce)

Many participants described their perception that medical knowledge and expertise was valued above the specialist holistic knowledge they possessed and the valuable ethical understanding of the patient and family they could provide. However, it is difficult to determine from the findings whether the medical team undervalued holistic knowledge, whether they failed to recognise this knowledge could offer rich information for clinical-ethical decision-making, or whether they simply undervalued the extent to which nurses could provide this information. Nonetheless, many participants reported feeling they were excluded from decision-making and that their opinion wasn't valued. Peter et al. (2014) found similarly in their study exploring nurses' experiences of

aggressive care that biomedical knowledge held by medics was privileged and thus medics could dominate decisions about initiating and continuing life-sustaining treatment.

6.2.4 Epistemic Injustice towards Nurses

Participants described the perception that they were recipients of ‘epistemic injustice’. I mentioned this concept briefly in chapter 3 as it was discussed in a theoretical paper by Reed and Rishel (2015) and thought to be a source of moral distress. The notion of epistemic injustice is based upon the work of Fricker (2007) who argues that injustice can be done against an individual in a distinctly epistemic sense: in their capacity as a knower. Fricker (2007) suggests there are two forms of epistemic injustice, testimonial and hermeneutic, both of which are evidenced in the narratives.

(a) Testimonial Injustice

Testimonial injustice (testimonial injustice) can broadly be of two kinds – a credibility excess or a credibility deficit –the speaker either receives more credibility than they ought to, or they receive less²⁵. In the previous section, I suggested that consultants may be recipients of a credibility excess because participants suggested their opinions were often accepted as true and justified

²⁵ Although Fricker (2007) discusses how a credibility excess is not an injustice in the same way that credibility deficit is because it is less likely to be a systematic injustice that can track an individual through various social, economic, political, professional, educational spheres, thereby increasing one’s vulnerability to other forms of injustice (see Fricker, 2007, p.27).

in virtue of their medical expertise. Whereas nurses described feeling they were recipients of credibility deficit. In the next quotation, senior nurse Grace describes her experience of trying to discuss the resuscitations status of a rapidly deteriorating patient and her belief that cardiopulmonary resuscitation (CPR) was inappropriate and the consultant dismissing her opinion.

“...when we were speaking and I was trying to explain to this consultant like why I really don’t think we should – why it’s not appropriate and how it’s not particularly fair and he said to me like, ‘Oh, I normally respect your opinion but today I don’t, so stop talking’ and he was so rude and he said that in front of like the whole ward round and it was just like, ‘Right, okay. Great’”. (Grace)

Although Grace suggests that the consultant usually respects her opinion, it seems that regarding this decision he did not, and many participants reported similar experiences in which their contribution was disrespected and ignored. Many participants described feeling they worked in environments in which it was common to feel ignored and disrespected. It would be an unfair representation of the data to state that all participants felt this way but it certainly seemed to be a majority opinion. In Grace’s narrative, the experience of testimonial injustice seemed to exacerbate the moral conflict she was already engaged in with the consultant, heightening her negative emotions and moral distress. This is an example in which the feelings of distress were not causally related to a moral event because of other-regarding emotions but rather because the nurse felt the responsibility owed to her was disregarded, creating a moral event in which she felt wronged. Had the consultant listened to Grace’s concerns and explained why CPR was indicated, even if she hadn’t changed her opinion she would have felt listened to, potentially reducing her moral distress.

Engaging in moral discussions and conflicts regarding the resuscitation status of patients is an unavoidable issue in ICU. However, the way in which healthcare professionals engage in these discussions and conflicts is manageable, and respectful communication is likely to reduce moral distress.

In the next quotation, Lily suggests that even a senior nurse was the recipient of testimonial injustice as she tried to articulate her belief that life-sustaining treatment was futile. This experience seemed to exacerbate the nurse's feelings of powerlessness and heightened her moral distress, not only because she was obligated to continue providing life-sustaining treatment but her opinion was also reportedly disregarded, and therefore she also felt morally wronged.

*"I wasn't the nurse there that night but the nurse who was there said that she felt powerless because she could see what was going on and you try to explain that it's not going anywhere, you know? We are doing everything and it's all max and it's a decision to actually to say this ends now, there is no point, and you can point out as much as you want but the nurse who was actually a Band 6 charge nurse and even she couldn't get it across."
(Lily)*

(b) Hermeneutical injustice

Hermeneutic injustice (hermeneutic injustice), in contrast to testimonial injustice, is experienced by groups of people, and Fricker (2007) suggests it is a structural identity prejudice. Fricker (2007) defines hermeneutic injustice as, "the injustice of having some significant areas of one's social experience obscured from collective understanding owing to a structural identity prejudice in the collective hermeneutical resource" (p.155). Fricker (2007) suggests that hermeneutic injustice arises because of a collective lack of understanding which prevents the knower from understanding their own social experience.

In the next quotation, Danielle discusses her frustration because she is not able to understand why interventions or care plans are initiated and continued. This may be because consultants don't think nurses will understand their decisions and is therefore a form of credibility deficit, or it may be evidence of hermeneutic injustice and deeper, structural identity problems.

“...most of the time we can see a death coming. A lot of the time we think what we're doing is futile and prolonging patient and family pain. And if this isn't the case then we need to be told why we're doing it. We need to be educated by the doctors as to why are we doing these things because unless I'm missing some massive part of it all, I've done things they've made no difference. The patient still died. I thought they we're going to die a week ago.” (Danielle)

Many participants described feeling their medical colleagues failed to understand their role and the importance of understanding the rationale for treatment decisions, especially considering they were often responsible for enacting these decisions. Participants also seemed to suggest that sustained proximity to pain and suffering intensified their feelings. Given the causal pathway and the requirements of empathy and proximity, it makes sense that sustained proximity could intensify distress. Olivia discusses this in the next quotation, as she emphasises the emotional strain of spending long days at the bedside:

“Maybe we don't see things as they see them and we shouldn't because we're not doctors, we're nurses, but I don't think that they get it, they might say that they do but I don't think they understand what our role actually is, and they don't get that 12 hours... you say could you imagine spending 12 hours in a side room with that one patient? And I don't think they do, no matter how much they say they do, I don't think they do.” (Olivia)

Fricker (2007) uses the example of sexual harassment to explain how experiences of hermeneutic injustice are not only a form of hermeneutic disadvantage but are an injustice and a form of “structural discrimination” (p.161). Fricker’s example is of a woman who works in academia and suffered sexual harassment at work but because it was not yet an established term, she struggled to understand and name her experience. Fricker (2007) emphasises how this is an injustice because of the social position of women during second-wave feminism. Women were still socially powerless in relation to men, and especially in areas such as academia. As I argued in chapter 2, a feminist study does not need to be concerned solely with women but with marginalised groups. The testimonial injustice and hermeneutic injustice experienced by participants (both men and women) in this study is evidence of nurses’ marginalisation within the healthcare hierarchy. Participants described working in environments in which the full extent of the nursing role, their responsibilities and the value of their knowledge was not understood by other healthcare professionals (hermeneutic injustice) and their opinion was often disregarded (testimonial injustice).

Peter et al. (2014) and Reed and Rishel (2015) also identified epistemic injustice as a possible cause of moral distress (as mentioned in chapter 3). Indeed, participants in this study that expressed feeling the effects of testimonial injustice and hermeneutic injustice (although not named explicitly) seemed to experience negative emotions because of epistemic injustice itself. It seemed therefore that in some situations epistemic injustice could serve as the moral event (an injustice and a type of moral constraint) that caused the negative

emotions associated with moral distress and the causal relationship was either of self-empathy or feeling that personal/professional responsibility was owed to them. Indeed, Scully (2018) argues that individuals suffering testimonial injustice are “being denied equal moral status with other humans within their community, and this is an important wrong even if the epistemic injustice is apparently the only way in which such status is being denied” (p.111). Although Scully (2018) notes that due to the social and political forces that impact epistemic injustice, it is unlikely to be the only way the individual is wronged.

In the next quotation, Kayleigh describes a moral conflict concerning the care of a young patient. Kayleigh describes how many nurses felt the patient was receiving futile life-sustaining treatment and experienced the negative emotions associated with moral distress because they were obligated to continue providing life-sustaining treatment. However, Kayleigh seems to suggest this moral conflict was exacerbated and her negative emotions intensified because the consultant failed to appreciate the nurses’ role and did not explain the reasons for continuing treatment (hermeneutic injustice).

“...no-one wants to see a young patient die but even now I don't understand and he would have been a really good person to have a de-brief about because none of us, even now, he's still there, none of us understand why he's been there all this time and why he's gone through what he's gone through.... I guess I would like a sit down with the doctor to ask what her rationale was. If I understood her rationale, but I really don't think she had one which is why it was so frustrating.” (Kayleigh)

In the next quote, senior nurse Phoebe describes her perception that junior nurses lose their confidence due to repeated failed attempts to integrate themselves into decision-making. Phoebe suggests that when their viewpoint appears to be disregarded, they feel disrespected, lose their confidence and stop

trying. Phoebe suggests the presence of epistemic injustice when she states, *“they don't expect you to understand, this is just what we're doing”*. This suggests that nurses do not enter the healthcare environment viewing their role or knowledge contribution as of lower value, but are forced to accept the hierarchy because of repeated failed attempts to infiltrate it.

“I think because there's often, there's not one on one, there's always a team of doctors so on the ward round this morning there'll be a consultant and registrar and two junior doctors so that's four people for a junior nurse to stand in front of four doctors and go..., when they don't have much knowledge behind it, to just say... "well I don't really think we're doing the right thing" can be very, very difficult and very challenging and also because sometimes the doctors can be rude to the nurses. It happens, they can brush them off, they can be rude and say you know they don't expect you to understand, this is just what we're doing and I think when that happens once or twice or they've heard that their colleagues have had that happen, it knocks their confidence as well, so I think it's a bit of both.” (Phoebe)

6.2.5 Epistemic Injustice towards Family

Participants also described the family as recipients of epistemic injustice, and this also seemed to exacerbate their experiences of moral distress because epistemic injustice made managing moral events more difficult. In the next quotation, Rebecca talks about her perception that the healthcare team failed to fully explain the patient's poor prognosis to the family, meaning they weren't prepared for the patient's death.

“They didn't really make it clear that he wasn't great and they just said in the next few days we're waiting to see if he wakes up and it kind of made me think that's what we've been doing for the last couple of weeks. How is it that you can tell them that that's what you're doing for the next few days as opposed to the last two weeks. You've been waiting and watching for the last two weeks - why is there nothing else you can tell them at this point - why is it going to be different in 3 days time when he hasn't done anything.” (Rebecca)

Most often the epistemic injustice towards families seemed to be in the form of hermeneutic injustice - participants described working within teams that seemed to ascribe to the view that until a prognosis was verified and ‘certain’ they shouldn’t share information. This meant that even if participants felt the family ought to know, their opinion was disregarded and over-ruled. Again, this seemed to exacerbate the moral conflict with an additional constraint and participants felt they had been wrong and that they were implicated in deceit, thus exacerbating moral distress. Presumably, clinicians were afraid of revealing a prognosis until they had empirical data to support it. The medical teams control over how and what information was shared with the family evidences their ‘epistemic authority’ as their social and material power allows them to legitimately enforce this epistemic practice (Scully, 2018).

This also represents an inability to fully comprehend families’ experiences of critical care and how privileging medical information ensures the doctor(s) and nurse(s) yield more power. Carel and Kidd (2014) argue that “certain policies, practices and cultural norms within modern healthcare practice are liable to generate epistemic injustice” because healthcare practice privilege certain types of testimony, forms of evidence and methods of sharing knowledge above others (p.531). This practice of only revealing a prognosis once it has been verified through tests and scans generates epistemic injustice and may exacerbate moral distress. However, the idea of prognostic certainty is somewhat of a misnomer as there is almost always a level of uncertainty. Indeed, this practice of only revealing prognoses once they are verified could

contribute to some families feeling deceived by healthcare professionals and contribute to the break-down of trust that is sometimes experienced between families and clinicians.

6.2.6 Roster Lottery

Interwoven with participants' reports that consultants made the most important decisions, were reports that these decisions were highly variable. Participants discussed how certain consultants would delay decisions or never made decisions to withdraw life-sustaining treatment. Participants discussed strategising and waiting until consultants were working that they thought would be more likely to a) make a decision and b) make a decision to withdraw life-sustaining treatment before raising their concerns. In the next quotation, Joyce describes her perception that consultant variability, or the 'roster lottery' delayed decision-making and meant patients continued with futile care for longer.

"I think ethically everyone has their own perspective on things... it's difficult because every consultant, when the consultants change every week, they've got their own ideas of what's best for someone and when you see who's on next week, oh great and who's on next week it might be people plodding along until the following week and the next consultant comes on and says 'right okay this is futile so....' (Joyce)

The term 'roster lottery' is taken from Wilkinson and Truog (2013) who discussed some of the ethical implications of physician variability in end-of-life decision-making, and hypothesised that this could be a source of moral distress. Indeed, the delays in decision-making caused by the 'roster lottery' seemed to be a compounding factor which exacerbated moral conflicts because nurses felt constrained for longer periods of time. However, participants in this study

seemed to be less concerned with the ethical implications of variability itself, and more concerned by the effects of the variability, namely, a perceived increase in suffering for the patient because of delays and epistemic injustice towards the family because prognostication was vague.

6.2.7 Summary of Theme

Participants described the different ways they felt excluded from clinical-ethical decision-making. Participants felt that medical knowledge was valued above holistic knowledge, and holistic knowledge wasn't recognised as having value for clinical-ethical decision-making. Some participants described feeling epistemically excluded and experienced different forms of epistemic injustice which further accentuated power differentials between members of the healthcare team. This had the effect of making participants feel additionally constrained because they were unable to contribute to decision-making and exacerbated their experiences of moral distress, and in some cases seemed to serve as the moral event itself. The need to make decisions in ICU is unavoidable, however the findings suggest that if nurses are involved and able to contribute to decision-making, this can help mitigate their experiences of moral distress by reducing the extent to which they feel morally constrained. Furthermore, recognising that nurses hold specialist holistic knowledge that is valuable for clinical-ethical decision-making means that nurses can be regarded as a useful resource for these decisions, thus potentially reducing moral distress.

6.3 Responsibilities

Participants feelings of responsibility constituted the causal chain between themselves and the moral event, and seems required (with/without empathy) for an experience to be labelled 'moral distress'. However, participants also reported feeling distressed when they felt torn and conflicted because of the different pulls of their responsibilities. In these situations, the conflicting responsibilities seemed to constitute the moral event in itself and feelings of self-empathy constituted the causal relation. Within this section I discuss the responsibilities that emerged as common themes in the data.

6.3.1 Professional vs. personal responsibilities

Participants felt responsible for patients not only in a professional capacity as their designated nurse but also on a personal level. These feelings constituted both the causal connection between themselves and patients, and when they conflicted they could exacerbate or constitute moral events in themselves. For example, when participants described experiencing moral uncertainty (moral event) because of the conflict between their personal and professional feelings of responsibility. When there was a conflict between these responsibilities, participants discussed fulfilling their professional responsibilities above their personal values. In the next quotations, both Jenna and Max discuss fulfilling their professional duties despite personally feeling they weren't necessarily doing the right thing. In previous literature, this may have been interpreted as participants acting contra to their moral integrity (for example Hamric (2014), but participants didn't frame their experiences in this way. Jenna compared her beliefs to her emotions and described feeling led by her emotions, and Max

described his belief as a *“feeling”*. Not only does this language suggest a lack of moral certainty in their moral judgements but it also suggests participants naturally tended towards more feminist conceptions of morality in which one’s feelings and emotions are a legitimate guide to moral judgments rather than set aside as irrational and unreliable. However, neither Max nor Jenna seem to actually subscribe to this view because they both discuss setting these personal feelings aside in order to fulfil their duties.

GM: “Obviously, we've discussed that situation and you now feel you weren't doing the right thing but you did at the time, or like you still did it... is that because you felt professionally you had to do it?”

Jenna: “Yeah I think so. I don't really think of it in terms of belief but my own emotion, say if I was really emotionally attached, like affected by something, I wouldn't let that show because I'd want to be seen to be professional so I don't know maybe I get my beliefs by my emotions, that sort of thing. You want to be seen to be doing the right thing for the family and the patient. It's a tough one. Sorry that's not a very good answer.”

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“Well there is the feeling that the treatment you're doing is futile, there is a feeling that okay I'm going to carry on doing this because this is what I've got to do, this is the prescribed treatment and this is what they want us to do and it's not my decision to stop treatment, that's a medical decision so I will continue that if that is what the consultant wants us to do but I want to turn around and go I don't think this treatment is working and should we consider other options...” (Max)

Participants described the belief that acting in accordance with their professional duties was the right thing to do and to not allow their personal feelings to seep into their judgements. Whilst some participants seemed comfortable prioritising their professional responsibilities, for others there remained a sense of uncertainty and regret which seemed to linger and culminated in frustration and guilt - or moral residue – which signals the experience of a moral dilemma.

Conflict between personal and professional values is an unavoidable compounding factor. However, as with decision-making, participants' moral distress may be mitigated by discussing their viewpoint and feeling their concerns have been heard. This may be an additional reason why understanding the rationale for treatment decisions is so important - because participants need to know that their personal values are being overridden for a legitimate reason.

6.3.2 Nurse as advocate

The duty to act as a patient's advocate was a deeply held professional responsibility that motivated participants to act. In the following quotation, Kayleigh describes how this responsibility to advocate motivated her to "*protect*" the patient from other healthcare professionals. Kayleigh discusses the specialist holistic knowledge she gained from spending extended periods by the bed-space and how, unlike other healthcare professionals, she really got to know patients and families.

"I always feel a little bit protective of the family because you're the patient's advocate and they're in bed and can't make any decisions and you want to protect them and be there for them and it's one element that would slightly annoy me if healthcare professionals think they know something better and it's just like you were there for ten minutes, try being there for 12 hours, it's a totally different attitude you get of people and you can't judge people in a ten minute conversation with them when they are trying to just cope with the most difficult thing they have ever had to deal with in their entire life." (Kayleigh)

Historically, the notion of advocacy was adopted to empower nurses and free them from subservience (Kuhse, 1997). Indeed, this seems to be how it was employed by the participants – it provided a reason and justification for engaging in decision-making and empowered them to enter moral conflicts with other healthcare professionals. As Kuhse (1997) argues, advocacy emphasised

the importance of assertiveness and courage rather than submissiveness and unquestioning obedience which had been characteristic of nursing in the late 19th and early 20th century.

Despite the fact participants felt empowered by the imperative to advocate, their attempts were often thwarted because their agency remained constrained and limited. They were limited because decision-making authority rested with consultants and, likely due to hermeneutic injustice, they seemed to feel they weren't privy to all relevant information; describing incidents where they would learn key pieces of information late on. In this way epistemic injustice could constrain their attempts to advocate for patients. As a result, they experienced inner conflict because their sense of duty and expectations of themselves were at odds and this seemed to either cause or exacerbate moral distress experiences.

Nurse commentators have recently illuminated these negative aspects of advocacy and the courage required to advocate. Hamric et al. (2015b) argue that calls for 'moral courage', the virtue to speak out against clinicians when you believe a wrong is being committed, have become overly-burdensome. They quote Tessman (2005), who argues that calls for courage can be oppressive in certain circumstances and deflect away from the responsibilities of those whose job it is to create environments that do not require such levels of courage (Hamric et al., 2015). Indeed, the same can be said for advocacy. If environments were such that nurses could be part of decision-making, they would not be required to exercise courage to advocate.

Shannon (2016) suggests that advocacy represented a historical shift of nurses' accountability from doctors or employers to their patient's, and suggests advocacy can be harmful to collaborative relationships. Indeed, Kayleigh's quotation supports this as she suggests her role as advocate meant she knew more about the patient than other healthcare professionals, thus creating barriers and possible conflict between the team rather than bringing them together in collaboration. In the past, nurses (female) were empowered by adopting the patients voice to challenge the physician (male) (Shannon, 2016). Shannon (2016) argues that this shift has resulted in nurses seeing themselves as 'The Patient Advocate', rather than *one of* the patient's advocates, and argues that this is damaging to the collaborative team who all view themselves as advocates.

Shannon (2016) suggests that "Unintentionally, using advocacy as a way to communicate ethical and legal equity may have exacerbated longstanding professional conflicts and power inequities within health care" (p. S46). The patient's voice therefore remains at risk of being lost within the conflict. Indeed, there is a sense in which the participants were using advocacy as a weapon in conflicts with physicians and prevented the team from coming together with a common goal: to fulfill the patient's best interests. As with many of the other compounding factors that I have discussed in this section, issues related to advocacy (both participants' drive to advocate and their inability to advocate) seemed to indicate poor team dynamics and epistemic injustice as participants reported feeling excluded from decision-making. Participants' attempts to advocate highlighted the ways in which they were morally constrained and

exacerbated moral distress. I suggest that the responsibility to act as patient advocate is an unavoidable responsibility but as Shannon (2016) suggests, the focus needs to be maintained on the patient's best interests and advocacy should not be used as a weapon between healthcare professionals.

6.3.3 Summary of Theme

Participants felt connected to patients through their personal and professional beliefs. However, when these came into conflict they could constitute the moral event that caused moral distress. The notion of advocacy seemed to complicate and exacerbate moral events by giving participants a false sense of empowerment. This meant that whilst they felt responsible for patients, as their advocate, they still reported having very little input regarding treatment decisions and care plans because ultimately, they were still required to enact others' decisions. This created conflict between the participants' expectations of themselves and the reality of their circumstances.

The requirement to enact others' decisions is unavoidable as nurses in ICU are responsible for the continuous care and monitoring of critically ill patients. The severity of patients' illness in ICU means that care needs to be led by medical experts. However, participants have indicated that a greater awareness of nurses responsibilities could help to alleviate moral distress. For example, recognising that nurses are responsible for enacting treatment and ensuring they agree with treatment decisions could reduce the extent to which they feel constrained and powerless.

6.4 Relationships

Participants discussed the many relationships they navigated on a daily basis: with doctors, families, patients and nursing colleagues. In the previous sections, I have painted a picture of poor team dynamics, conflict and a lack of respect for nurses' viewpoints largely driven by power imbalances between nurses and medics. However, some of the working relationships described by participants were more harmonious and built on mutual respect. When participants perceived working relationships to be good, they described more positive working environments. Positive working environments seemed to be ones in which participants felt they could open-up and share their thoughts and values. Conversely, when relationships were bad, participants described negative environments that were filled with mistrust.

6.4.1 Team Dynamics

When moral conflicts and moral dilemmas arose, participants that felt able to contribute to clinical-ethical decision-making, felt respected and empowered. Consequently, the moral distress associated with the moral event seemed to be mitigated. In the next quotation, Kayleigh describes how a new consultant asked her opinion regarding whether they should withdraw life-sustaining treatment. In this situation, Kayleigh wanted to give the patient a couple more hours before she felt they could say with more confidence that the patient wasn't going to recover. Despite Kayleigh's belief that the patient would die anyway, she reflects upon the opportunity she had to provide her perspective. This meant she could withdraw life-sustaining treatment in full agreement of the decision. She did not feel the frustration, anger or powerlessness that characterises moral

distress during similar moral events. Kayleigh also categorised consultants as good or bad depending on the extent to which they involved nurses in decision-making.

“... some of the newer consultants like the lead of our unit and lots of other people, they will always turn to the bedside nurse and say are you happy with that plan? What do you think? What do you think they would want to do? and X said to me before when I was a bedside nurse, 'I don't think there is anything we can do, this patient is going to die, we have tried everything, do you agree? I think at this point we should just cap the treatment and let nature take its course.' and I've been 'I'm not sure' ... Those kinds of people, they will listen and say, 'if that's what you think will make a difference then let's give it a try' and for that patient it really didn't but he was willing to give that time because the patient wasn't in distress or anything but they were also not going to live and so what's two hours in terms of making a decision. But I feel it just goes to show good consultants against bad consultants and whether or not they include the bedside nurse and care about their opinion too. So, there are always those times when the bedside nurse may feel what we are doing is futile and maybe we should let someone pass away with a little bit of dignity...”
(Kayleigh)

Kayleigh's and other participants' experiences seemed to suggest that being part of decision-making mitigated moral distress. This is supported in another study, reported in Peden-McAlpine et al. (2015) and Traudt et al. (2016) in which 19 experienced critical care nurses were interviewed who had self-identified as skilled and comfortable during end-of-life care. Instead of discussing their experiences of moral distress, the nurses, who had an average of 17 years' critical care experience, reported feeling a strong sense of moral agency, felt accountable for their actions, possessed 'moral imagination' (meaning they could empathise and appreciate the values of others), and perceived a 'moral community' in which they viewed themselves as integral to decision-making (Traudt et al.,2016). This suggests that if we cultivate environments in which

nurses feel valued and their opinions are integrated into decision-making, then moral distress may be mitigated.

In contrast to Kayleigh's experience, senior nurse Rachel expresses her frustration because she felt morally constrained because she felt she couldn't articulate her point of view. Rachel indicates mistrust of her colleagues as she suggests they would they simply ignore her and even vindictively do the opposite to her suggestion. Peter and Liaschenko (2013) suggest that moral distress may be a reaction to the recognition that others cannot be trusted. I suggest that in this instance, moral distress is caused by moral constraint and is exacerbated by feelings of mistrust due to poor team dynamics. Rachel's perspective also supports the findings in the theme 'Roster Lottery' in which nurses reported strategising and waiting to speak to consultants they believed would be more open to their viewpoint before raising concerns.

“...it depends on who they are ... it's knowing the personalities of the newer anaesthetists and knowing how to speak to them really sometimes there's no point in even trying to bring something up with that one because they'll just ignore you and do their own thing in a way and some of them, because you've said it, will do the opposite, do you know, that's really frustrating...” (Rachel)

6.4.2 Summary of Theme

Participant reports suggested that poor team dynamics, poor relationships and poor communication contributed to negative working environments which exacerbated and increased the perceived difficulty of managing moral events because nurses felt their viewpoints were not valued. These factors all seemed to contribute to the perception of a negative working environment. The notion

that moral distress is correlated to the ethical climate of an institution is well documented in the literature with correlations identified between higher moral distress scores (using the MDS and MDS-R) and negative perceptions of hospital or unit ethical climate (Corley et al., 2005; Hamric & Blackhall, 2007; Silén et al., 2011; Hamric et al., 2012; Whitehead et al., 2014).

Many moral events are unavoidable, but the way in which they transpire can be managed. Corley et al. (2005) explored moral distress and ethical climate using the Ethical Environment Questionnaire, and the lowest scoring item was: 'I am involved in deliberations addressing ethics concerns about my work'; the implication being that the more involved in ethical deliberations the nurses were, the less moral distress they felt. Indeed, nurses in this study seemed to feel more satisfied with the way moral events were managed when they were involved in and understood the rationale for treatment decisions.

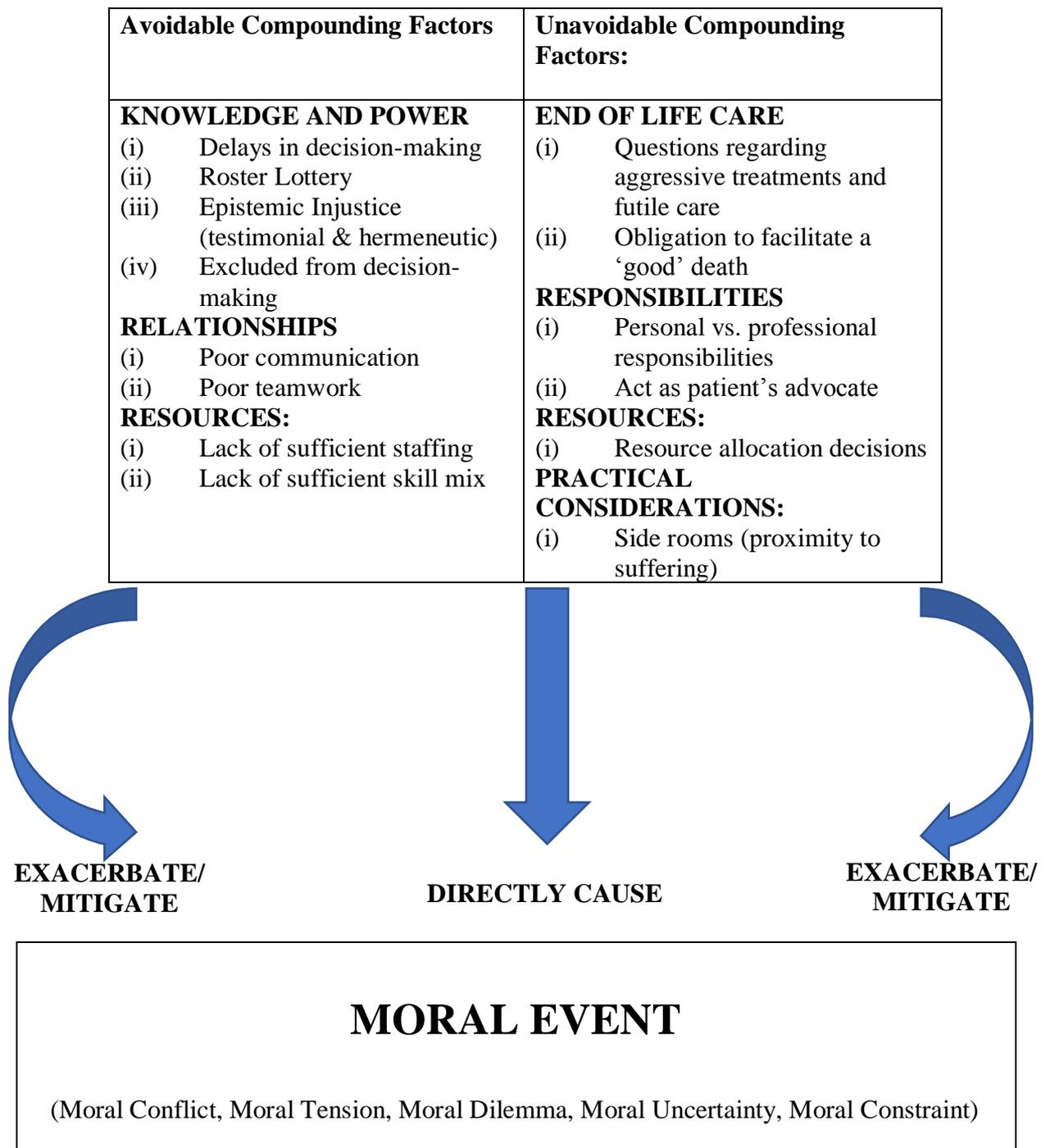
However, it is important to recognise that the extent to which nurses were involved seemed to be dependent upon individuals and therefore we need to provide solutions that can be tailored to individuals and not only focus on entire institutions. Individuals need to be provided with the knowledge and skills to communicate and navigate ethical problems and difficult relationships.

6.5 Conclusion

In this chapter, I discussed the compounding factors that can affect the way moral events are managed, and either cause or exacerbate participants experiences of moral distress. Many of these compounding factors seemed to

capture the sense of the unit or institutions ethical climate. Further exploration is needed of these compounding factors and the extent to which they impact nurses perceptions of ethical climate. I have highlighted the factors which may be regarded as avoidable/unavoidable, and this is shown in Figure 6.

Figure 6: Compounding Factors



CHAPTER 7- REFLEXIVE BALANCING

7.1 Introduction

Within this chapter, using the method of reflexive balancing (reflexive balancing), I will systematically challenge my account of moral distress to ensure the definition is as robust as possible. reflexive balancing was first explained in chapter 2 but I recap the main steps here for clarity. reflexive balancing is based on quasi-moral foundationalism. This means that for the purposes of ethical inquiry, I treat some beliefs as if they are epistemically privileged. These are my boundary principles. These beliefs are relatively secure, however if there are substantial, undefeatable challenges that threaten the coherence of these beliefs then these principles can be adjusted or abandoned. Ives (2014) suggests that these epistemically privileged beliefs should be derived from the data in an attempt to reduce the impact of researcher bias. However, I am slightly deviating from Ives (2014) method by deriving my boundary principles from the data and from my commitment to ‘core feminism’: to seek and eradicate sexism and other oppressions (Donchin and Purdy, 1999). These commitments amount to the rather uncontroversial claims that women and oppressed individuals’ experiences have epistemic value, women should have equal status to men and that oppression is morally wrong and should be eradicated. I will still interrogate and question participants’ experiences but I will not question their validity. I take their accounts to be a true representation of their perceived experiences.

Treating these non-empirically derived beliefs as privileged is justified on the basis that they are relatively uncontroversial.²⁶ These beliefs hold some inherent bias towards certain claims over others, but I suggest this is a positive bias because the aim is to correct injustice and achieve equality. Furthermore, because these beliefs are only treated as if they are epistemically privileged, they are not immune to challenges and therefore, if there were an insurmountable challenge which rendered these beliefs incoherent then they could be adjusted or abandoned if necessary.

As discussed in chapter 2, these principles have provided the basis for this project. In this chapter, I will argue that because of these commitments and the values they entail, they also drive many arguments regarding why we ought to accept a broader definition of moral distress.

In addition to my feminist commitments, the following empirically-informed definition also acts as my boundary principles:

I suggest moral distress is the combination of:

- (i) the experience of a moral event

'Moral event' could be any/combination of the following: moral tension, moral conflict, moral dilemma, moral uncertainty or moral constraint.

²⁶ These beliefs are relatively uncontroversial in the western world but of course women suffer great oppression in other parts of the world. In such places where this oppression is an accepted norm, it is likely this account of moral distress may be perceived to be incoherent.

(ii) the experience of 'psychological distress'

The term 'psychological distress' is an umbrella term that captures a variety of different negative emotions that may be expressed differently by each individual but the predominant emotions amongst these participants were anger, frustration, guilt, regret, sadness/upset, powerlessness, symptoms associated with stress and feeling torn.

and

(iii) direct causal relation between (i) and (ii)

This causal relationship may be explained using the following 'Causal Criteria':

- 1. There is a feeling of either: other-regarding or self-directed empathy for the individual(s) involved in the moral event; and/or recognition and acceptance of a feeling of personal/professional responsibility to those involved in the moral event, including towards oneself.*
- 2. The nurse has a proximate relationship to the moral event in time and space.*
- 3. The nurse experiences a combination of emotions that may be regarded as falling within the umbrella emotion 'distress' following involvement in the moral event.*

Following the literature review, I suggested the above three conditions seemed to be required for moral distress to occur: a moral event, psychological distress and a causal relationship. This definition was further refined using the empirical data and nurses' 'encounters with experience' (Ives, 2008), and will act as my

null hypothesis to be tested in this chapter using disconfirming data, relevant questions left unanswered at the end of chapter 3 and challenges from the literature. If I can satisfactorily defend my account then it is arguably a robust account of moral distress.

From my account of moral distress, I also develop second-order judgements regarding how we ought to respond to moral distress. This satisfies the normative mandate which accompanies the commitment to core feminism by seeking to eradicate oppression. These second-order judgements should cohere with the boundary principles, however if they do not, because the boundary principles are only treated as though they are epistemically privileged, they can be altered if required. In order achieve coherence, the emphasis will be on reaching practical and justifiable normative recommendations.

After posing three key challenges to the suggested definition of moral distress, I present the ‘Moral Distress Model’ and explain how each element interacts with moral distress. I will introduce some additional data in this final chapter. Primarily, this is for the purposes of presenting deviant cases and supporting the model with findings. Where the data are presented for the first time, I make this clear, and, where data are discussed for a second time, I provide links back to the original presentation. Presenting results at this stage is unusual and differs to standard reporting in an empirical thesis. However, it is accepted that within empirical bioethics deviations such as these do sometimes occur and the emphasis is upon justifying and being transparent about such deviations (Frith and Draper, 2017). As I am moving between theory, empirical data, results and

normative conclusions in an iterative fashion, it is necessary that each element is weaved throughout the thesis. The empirical data I present in this chapter inform the normative recommendations and conclusions, and are therefore most suitably presented here.

7.2 Three Challenges

I will begin this discussion by raising three challenges that may be levelled at this broader definition.

(i) Challenge 1: It's too broad

Within this challenge, there are four key criticisms that can be made of this definition for being too broad. First, the 'term of art' criticism. Second, that constraint is the only cause of moral distress. Third, even if we concede other possible causes of moral distress, constraint remains the most prevalent and most distressing cause and finally, that broadening the definition makes it diagnostically and analytically meaningless.

The first argument is based on the claim that moral distress is a term of art coined to capture the specific phenomenon of constrained moral judgement observed by Jameton (1984) (Campbell et al., 2016), and we ought therefore to preserve it (Morreim, 2016). On this argument, simply appealing to the meaning of the words 'moral' and 'distress' does not resolve the issue of what moral distress means and instead there must be an examination of the key features of the phenomenon (Campbell et al., 2016). However, this argument does not provide us with a strong justification against reconceptualising moral distress if

this increases its utility and relevance. If, by examining the key features, we find good enough reason to reconceptualise the phenomenon, then it seems we ought to do so.

The second, and indeed stronger argument, is that constraint simply is the only morally-relevant cause of moral distress and therefore we have no need to broaden Jameton's original definition. In this section, I will examine whether we can legitimately claim that constraint is the only cause of moral distress by exploring some accounts of moral distress.

There is lots of empirical evidence to suggest that moral constraint causes distress, and this is captured in chapter 5.²⁷ There is also evidence to suggest that constraint not only causes moral distress but characterises it as an experience of moral distress. Rachel suggests in the next quotation that it is the unfairness associated with moral constraint that makes an experience distinctly 'moral distress'.

GM: "I want to try and figure out, what do you think is the commonality between all of these experiences that you've had that have caused you to find them morally distressing? What do you think is at the core of it?"

Rachel: "I guess it's the unfairness, isn't it, in every aspect really. I think when it comes to end of life I don't think that's necessarily unfair, I just don't want people to suffer and I want to make them comfortable. I think it's the end of their life, let's admit it... it's difficult sometimes when what you think isn't happening and you've still got to give your care and empathy, but I think the most morally distressing things are when you disagree and you just think that's wrong, you're not doing what's best for the patient."

(first presentation of data – as deviant case)

²⁷ Predominantly section 5.3.1 – see also, 5.2.1, 5.2.3, 5.2.7

However, also captured in chapter 5, are the empirical data that indicate constraint wasn't the only cause of distress.²⁸ Participants discussed how other moral events caused similar negative emotional responses to constraint experiences. I will explore two experiences in which moral uncertainty is thought to have caused moral distress. The first is Beth's experience, first discussed in chapter 5. I suggested that Beth was experiencing moral distress in response to both constraint and uncertainty:

“I could see her distress and that she was so upset and it just made me feel guilty. No matter how right I knew I was on a practical level, you know, seeing how it made her feel, it just, made me feel guilty.” (Beth)
(first presented in chapter 5, section 5.2.3)

I also proposed that Beth was describing feelings of immediate and lingering guilt because she felt both constrained and uncertain about whether she should fulfil her professional obligation to continue providing life-sustaining treatment (suctioning an artificial airway) or fulfil her personal feeling of relational responsibility and refuse to suction the airway. For now, I want to focus on the previous quotation and Beth's immediate feelings of guilt and I will discuss the lingering guilt (shown in the following quotation) later in this section.

“I still felt guilty because I knew she didn't want me to do it, and as I say we are taught from day one about autonomy and about capacity and consent, and I knew she had capacity and technically she was not giving me consent to suction her via her trache[ostomy] but it's that very hard grey area of best interests, you know? I'm not allowed to just allow you to plug off, so it is difficult. It's hard when you try to say right and wrong which is the difficult part of it but I knew I needed to do these things but it didn't stop me from feeling guilty about it.” (Beth)
(first presented in chapter 5, section 5.2.3)

²⁸ Section 5.3.2, 5.3.3, 5.3.4, 5.3.5

Let us compare Beth's experience of moral distress to a case study example provided by Campbell et al. (2016) of a junior surgeon who, they argued, was also experiencing moral distress because of uncertainty. I use this example because the arguments that Wocial (2016) levels at Campbell et al.'s account could also potentially be levelled at my interpretation of Beth's account.

Campbell et al. (2016) provided the example of a junior surgeon who they suggested was uncertain about what to do when given a disproportionate caseload of complex and potentially vulnerable patients. According to Campbell et al. (2016), the junior surgeon was worried that as a new surgeon he could harm these patients and he was morally uncertain about what to do. Should he continue performing surgeries for these patients or should he raise his concerns with his seniors? Wocial (2016) argues that in this example, moral distress is not caused by uncertainty but by an internal constraint and therefore falls within Jameton's (1984) original definition and does not motivate a broader understanding of moral distress.

Wocial (2016) suggests that Campbell et al.'s (2016) example is one of confidence rather than conscience and questions whether the junior surgeon's reluctance to do the right thing is a political rather than moral choice. Both Wocial (2016) and Epstein et al. (2016) suggest the surgeon is not really *morally* uncertain, he just lacks the confidence to question his seniors and fears the potential repercussions of doing so. This criticism could also be levelled at Beth: she isn't really uncertain, like the junior surgeon, the correct course of action is

clear but she just lacks confidence, is fearful of retribution and is therefore morally distressed because she is internally constrained. Morreim (2016) might argue that they aren't even experiencing moral distress because they aren't being prevented from carrying out the right action but rather they are conflicted about the level of self-sacrifice they are willing to undertake.

I have, however, three responses to these criticisms. Firstly, just because an observer can determine the correct course of moral action, doesn't mean the junior surgeon or Beth can. Secondly, if they frame their experiences in terms of feeling distressed because of uncertainty then we ought to respect their interpretation of the event. Thirdly, if they are experiencing distress because of the conflict between the 'right' thing to do and self-preservation, this falls within my broader definition and is an example of conflict between personal and professional values (moral event) causing psychological distress.

Nonetheless, later in Beth's narrative she described how she had in fact raised her concerns with the team who were in the process of carrying out psychiatric and legal assessments to see if withdrawal of life-sustaining treatment could be permitted. Despite knowing this, it didn't stop her from feeling uncertain about whether they were doing the right thing, or feeling constrained by her professional duties. Therefore, even if the junior surgeon sought advice from a senior colleague, we cannot say that this would have necessarily resolved the moral issue and he could have continued to feel uncertain and distressed.

Wocial (2016) states,

“even if the surgeon does not know exactly what is the correct course of action, he recognizes a sense of responsibility, feels powerless, is concerned for patient well-being, and believes there is personal risk regardless of the path chosen and to do nothing simply to protect himself would compromise his integrity... His struggle represents an internal constraint and could easily fall into the current understanding of moral distress. No new definition is needed for this case”. (p.22).

Here, Wocial (2016) is conceding that moral distress has occurred whilst the surgeon feels morally uncertain but she argues, because his experience already fulfils Jameton’s constraint criteria, there is no need for a new definition. However, in her theoretical paper, Fourie (2015) warns “if we limit distress to cases of constraint we may be dismissing the real-life experiences of many nurses” (p.97). I do not contest that constraint is an important cause of moral distress and this is supported by the empirical data, but I agree with Fourie (2015) that if there is sufficient evidence to suggest there are other causes of moral distress then we should not dismiss these experiences.

Morreim (2016) argues that the feeling of being “morally commandeered” that is caused by constraint is different to “moral puzzlement” and feelings of regret (p.28). The participants’ narratives support the notion that involvement in different moral events caused different emotional responses. However, there is very little evidence to suggest that constraint caused a special kind of emotional

distress. As shown in Table 12, there was a large amount of cross-over between moral events and predominant emotions expressed. The empirical evidence suggests that moral distress seemed to be characterised by participants as both caused and characterised by other moral events, not just constraint. In the next quotation, Holly characterises moral distress as feeling uncertain, conflicted and tormented about the right thing to do.

“Where you’re in torment and conflict because of the morality, the rightness or wrongness of a situation and it’s a very visceral thing, actually, I feel it’s sort of... it’s an instinctive thing, it’s a physical reaction almost that gets you before the consciousness of it.” (Holly)
(first presented in chapter 5, section 5.3.2)

Unlike Rachel, Holly’s moral distress experience is characterised by conflict and uncertainty. In the next quotation, Elizabeth suggests moral distress is characterised by uncertainty and constraint. These self-reports and others in chapter 5²⁹ give us reason to conclude that constraint is not the only cause of moral distress and furthermore, for some individual’s feeling constrained does not characterise a moral distress experience either.

²⁹ See for example Isabelle’s characterisation of moral distress in section 5.2.4 – she associates moral distress with moral dilemmas, describing it as “*some sort of tension that you can’t quite explain*”; and Elizabeth’s characterises moral distress in section 5.3.4 stating, “*I think the distress comes from that rock and a hard place and that’s definitely the crux of it*”.

GM: So, if I said to you, what is moral distress?

Elizabeth: "I think for me it comes out of a feeling of emotional or physical distress when you either don't feel like the right decision, well you feel like you followed a course of action or been complicit in a course of action which wasn't the correct one or where you are unsure as to whether it was the correct one, I think it can be either or, where yeah, that's what I would, where you're either faced with the decision or you've already done it and you are thinking that wasn't right or I don't know whether that was right or I think it was right but I can't be 100% sure. It happens all the time because you can never be 100%, yeah that's what I'd say it was."

(first presentation of data)

The question remains whether we have good enough justification to broaden the definition to include these experiences? Considering the boundary principles upon which my account must cohere and the commitment to attributing these accounts with epistemic value, to disregard these experiences or to suggest they are mistaken would be an act of testimonial injustice and would contribute to their oppression. Furthermore, by denying that these experiences fall within the lexicon of moral distress, we are preventing these individuals from making sense of their own moral experiences and associated emotions: a hermeneutic injustice. Scully (2018) argues that an individual suffering hermeneutic injustice will ultimately struggle to justify their choices and goals, make moral judgements and articulate their experiences as just or unjust. "In other words, through its [HIs] effects on important features of moral agency and identity, an impoverished *epistemic* capacity is also partway to producing impoverished *moral* capacity" (Scully, 2018, p.112). To disregard these experiences as moral distress, is therefore not only an epistemic wrong but a moral wrong as we deprive these individuals of the tools to make sense of their own moral experiences. It may be argued that we can find ways to respect these reports without necessarily incorporating them into the definition of moral distress but

the question still remains, if they aren't experiences of moral distress, then what are they?

One response could be that they are just ethically-challenging experiences and moral problems that cause individuals to feel troubled and upset, and they do not need to be regarded as cases of 'moral distress'. However, this response also seems to devalue the experiences; the implication being that participants' experiences aren't distressing enough, or distressing in the right way, to constitute moral distress. The years of moral distress research, largely conducted in North America, means that the concept has power in those contexts and when individuals report feeling morally distressed this implies that action should be taken to ameliorate their distress. Indeed, the power of the term can be seen in the recent responses to moral distress that have been developed, such as Hamric and Epstein's (2017) system wide moral distress consultation service. If these experiences aren't regarded as moral distress then, firstly, such services may never be set up in the UK because the level of moral distress might be regarded as too low (if restricted to constraint). Secondly, these services would not need to address these experience, since they aren't cases of moral distress. Latham (2016) suggests that a broader understanding of moral distress actually motivates a broader range of responses because it has "important consequences for the normative debate about what, if anything, one is obligated to do about one's moral distress" (p. 31). Indeed, physician ethicists Burgart and Kruse (2016) conduct clinical ethics consultations in the US and support expanding the definition because they suggest there is value in being able to

label and name the experiences that many healthcare professionals express during consultation of moral unease and uncertainty.

The aim of this thesis is twofold, to uncover and address oppression, and to build a coherent and justifiable picture of moral distress using empirical and theoretical literature, and nurses' real-life experiences. The most simple, justifiable and coherent answer - which values and respects these participants' experiences - is that these *are* experiences of moral distress. There is a growing body of literature that supports this conclusion and which suggests we gain a fuller understanding of moral distress by incorporating these experiences into the definition. Fourie (2015), for example suggests that Jameton's emphasis on constraint actually distorts the situation.

Fourie (2015) argues:

“...a definition of moral distress, which makes constraint central to distress, seems to distort the reality of the situation. Whilst constraint may be present and its significance should not be under-estimated... the case does not seem to be one that is accurately portrayed as being primarily about constraint: it is not simply that other people are arbitrarily or unfairly standing in the nurse's way but that they genuinely disagree with the nurse on a moral basis” (p.97)

In conjunction with the empirical data presented in chapter 5, I have shown there are other possible causes of moral distress aside from constraint, and that we have good reason to recognise these additional causes. However, there remain two more criticisms of this definition. The second objection of the broad

definition is that the most common and most distressing cause of moral distress is constraint and we should reserve this term for those experiences.

Moral constraint was a common cause of moral distress discussed by participants and, through extensive use of the MDS and MDS-R, we have evidence to suggest that constraint causes moral distress in many other settings. However, we cannot say with certainty that it is the most common cause because it is not widely accepted that there could be other causes of moral distress and therefore these have not been explored or measured to the same extent.

Regarding whether constraint causes the most distress, again, the evidence is ambiguous. In the next quotation, I ask senior nurse Phoebe whether she still feels moral distress when uncertain. Phoebe suggests she feels more distressed when uncertain than constrained because the uncertainty makes her feel more powerless and unable to even articulate an opinion.

GM: “So, in the situations where you're not totally sure that you know the right thing to do, do you think that would still cause you moral distress, would you still feel morally distressed?”

Phoebe: “Yeah because I'd then probably feel guilty that I knew it wasn't the right thing but I didn't know what the right thing was. That would almost probably make me feel worse.”

GM: “Yeah, really?”

Phoebe: “Yeah because I wouldn't be able to fight my corner. If I'm out there and I know that we're doing the wrong thing then I can say ‘this isn't right, what about this, what about this?’ I can verbalise what I'm thinking, what I'm feeling and then I can have feedback and I can have the doctor say well this, this and this and you can have a conversation about it, but I think those situations where it's like this isn't right but I don't know why, that causes me quite a lot of distress and then I would feel almost a bit guilty because I'm like I know we're not doing the right

*thing but I don't know what the right thing is and then I feel like I'm failing a little bit because I feel I should know what the right thing is.”
(first presentation of data)*

Wocial (2016) objects to characterising moral distress experiences according to severity level. She argues that Campbell et al.’s example of ‘mild distress’ as a case of moral distress shows an unsophisticated understanding of the literature, and Wocial (2016) argues that it is readily accepted that moral distress can be of different intensity levels, thus we cannot characterise moral distress based on this. Indeed, not only is it arbitrary to determine a moral distress experience based upon the severity of the distress, but it is also very difficult to measure and compare emotional experiences. Individuals react to and express their emotions in a variety of ways and it would be unfair to discount an experience of moral distress on the basis that it is not distressing enough to constitute moral distress proper.

The fourth criticism that I suggest could be levelled at this broader definition of moral distress is the risk of making it “diagnostically and analytically meaningless” (Wocial, 2016, p.21). Epstein et al. (2016) have similar worries as they stress the importance of a concept that is practical and which can help us to develop interventions to mitigate it. Fourie (2015) suggests reclassifying moral distress into its causal constituents so that moral distress caused by constraint is termed ‘moral-constraint distress’, moral distress caused by conflict is ‘moral-conflict distress’, moral distress caused by uncertainty ‘moral-uncertainty distress’ and so forth. By sub-categorising particular types of moral distress, this could in fact help researchers to develop more specific measures and targeted interventions for moral distress. These needn’t be

mutually exclusive either, as it is entirely possible that they may occur simultaneously. These sub-categories are broad enough to warrant slightly different interventions but are not overly specific. For example, a situation of ‘moral-dilemma distress’ or ‘moral-uncertainty distress’ may call for an ethics expert to help the team identify ethically-justifiable options, whereas ‘moral-conflict distress’ may require an expert in conflict-resolution to help restore communication and trust. In chapter 5, I also suggested that different emotions may be predominantly associated with certain moral events (see Table 12). If these associations are plausible, they could help nurses experiencing moral distress recognise the cause of their moral distress and seek the most relevant targeted response.

Epstein et al. (2016) argue that, “developing interventions for various subtypes would be extraordinarily challenging – how would one develop and test an intervention for moral distress... caused by moral uncertainty?” (p.17) However, this does not provide sufficient justification for disregarding other morally-relevant causes of moral distress, especially if ultimately these interventions are more efficient. Indeed, reporting on the system-wide moral distress consultation service, Harmric and Epstein (2017) reflect upon the fact that they found moral distress and moral dilemmas aren’t always mutually exclusive. Recognising that moral distress constitutes a broader range of moral events may improve such interventions.

To conclude this section, the charge that this definition is too broad is potentially the most damaging challenge. However, I have provided empirical data that

suggests there are other moral causes of moral distress and that these other causes characterise some individuals' moral distress experiences. I have provided good theoretical reasons why it is coherent to accept other causes of moral distress and why we ought to value the experiences of participants in this study. I have also provided practical reasons why expanding the concept may help researchers to develop more targeted responses. Importantly, I am not arguing that constraint does not cause moral distress or that broadening the definition makes moral constraint-distress any less worthy of action. In fact, I agree with Fourie (2016) who suggests that if nurses experience disproportionate amounts of constraint-distress (as seems likely considering their position in the hierarchy) then it is a matter of distributive justice that we continue trying to find ways to alleviate this distress.

(ii) Challenge 2: Knowing the right thing to do - a necessary condition of moral distress?

As discussed in the previous section Jameton's (1984,1993) and subsequent conceptions of moral distress have been built upon the assertion that moral distress only occurs when one has made a moral judgement but is constrained. In the previous section, I challenged whether constraint should be regarded as the only cause of moral distress. In this section, I will address what I anticipate to be the second substantial challenge of this broad definition – that moral judgement ought to be regarded as a necessary condition of moral distress. To respond to this, I first need to establish what is meant by the term 'moral judgement' because the terminology is currently ambiguous.

In chapter 3, I highlighted how the language used in previous definitions of moral distress has been unclear. Moral judgement has been referred to as a ‘decision’, ‘belief’ and an ‘awareness’ (Jameton 1984, 1993; Wilkinson 1987/88; Nathaniel 2006). This differing terminology suggests that ‘moral judgement’ can be interpreted as holding different epistemic strengths - an awareness seemingly being much weaker than a decision. On a weak account, a moral judgement could therefore be understood as occurring even when one is experiencing indecision – they may recognise there is a moral problem, make a moral judgement about certain facts being morally relevant but remain undecided about what is ‘right’. Whereas on a stronger account, the individual may recognise there is a moral problem, make a moral judgement about certain facts being morally relevant and feel certain they know what is ‘right’. Kushe (1997) argues that moral judgement should be understood in an even stronger sense and suggests that to make a moral judgement, we must be able to give reasons for our views. So, what does it mean to have made a ‘moral judgement’ and ‘know the right thing’ in the context of moral distress?

In this section I argue that we should understand ‘moral judgement’ in its weakest sense and that it should not be regarded as a necessary or sufficient condition of moral distress. The first reason for this is the variation and ambiguity regarding the way participants framed their moral judgements within their narratives. Below, I provide six excerpts from the data that were originally presented in chapter 5. In each of these excerpts, participants articulate their moral judgment in different ways:

1. “No matter how right I *knew* I was on a practical level, you know, seeing how it made her feel, it just, made me feel guilty.” (Beth)
2. “I don't *think* he should ever have been trach'ed...” (Joyce)
3. “...with lots of situations there are patients that you just *think*, what are we doing?” (Rachel)
4. “...you just *feel* like you're not doing the right thing with...” (Elizabeth)
5. “...you're in *torment* and *conflict* because of the morality, the rightness or wrongness of a situation...” (Holly)
6. “...it doesn't matter about my *feelings* because it's about the family, and it's about the patient and what they decided and so whatever my *opinions* on the subject, they aren't relevant...” (Amelia)

In the first quotation, Beth suggests she knew the right thing concerning the practical issue but expressed uncertainty about the ethical issue. In the second and third quotations, Joyce and Rachel both suggested *thinking they knew* and in the third Elizabeth discussed *feeling* she knew. In the fifth, Holly articulates *feeling* tormented and conflicted, and seems to be uncertain; and lastly, Amelia says that her *feelings* and *opinions* don't even matter. Participants most commonly expressed their judgements in terms of empathetic feeling rather than rules or judgements, which Jaggar (2001) suggests may be a more feminist approach to ethics. Participants describe a 'feeling of knowing' more akin to a moral intuition than a judgement and they do not indicate certainty which suggests moral distress can occur in a variety of epistemic states.

This variation in expression mirrors the variation in the existing definitions of

moral distress. I suggested in chapter 3 that, because the authors hadn't explicitly engaged with these differences in terminology, they disregarded the epistemological ambiguity these definitions created. The variation and subsequent ambiguity seems to suggest that we shouldn't take 'moral judgement' in its strongest sense but rather accept that moral distress occurs along a spectrum of epistemic strength.

The second reason I suggest we should accept moral judgement in its weakest sense is the complexity of clinical-ethical decision-making and prognostication. As Gallagher et al. (2015) highlight, medical decision-making and prognostication are rife with uncertainty, and yet they form the basis of clinical ethical decision-making. If we accept that the ethical supervenes on the natural then it seems likely that clinical uncertainty creates ethical uncertainty, and empirical evidence suggests this results in distress. Indeed, many participants discussed the difficulties of accurate prognostication and as Elizabeth describes, she experienced distress because she felt that decision-making was just guesswork- that they were gambling with other peoples' existence.

***“So, I think the distress comes from that rock and a hard place and that’s definitely the crux of it, it’s like I don’t feel comfortable standing here and it’s been months and month and months and just I feel like I’m dragging out this family’s pain and I may be dragging out your pain to like what end... and why are we doing this? And this doesn’t seem right and this doesn’t seem fair or nice. But on the other side you’ve got what feels like sometimes a little bit of a like educated guess... those are the ones that pop up in the night you know those are the faces where you’re just a bit like.... I think a lot of the time, I’ve never been in a situation where I don’t feel like we haven’t made the right choice but I’ve definitely, definitely been in the situation where I’ve spent a lot of time questioning it and yeah it’s that rock and a hard place, it’s that gamble on someone else’s existence, well it is, you’re gambling on their existence and what state that existence will be.” (Elizabeth)
(first presented in chapter 5, section 5.3.4)***

Other researchers have also suggested that the inherent uncertainty in prognostication and end-of-life decision-making causes moral distress. Oberle and Hughes (2001) interviewed nurses and doctors in acute care areas about their perceptions of ethical problems during end-of-life care. They found that the “defining feature” of end-of-life decision-making was uncertainty, and was a source of moral distress. They stated:

“...uncertainty about probable outcomes was the defining feature, leading to considerable deliberation and reflection about the ‘right thing to do’. At what point did patient suffering outweigh the probability of a positive outcome, and at what point should treatment be stopped? Even in the so-called futile cases there remained the possibility, however slight, that a positive outcome might result from further treatment” (p.710)

Dzeng (2017) reflects upon interviews she conducted with physicians regarding their experience of end-of-life care and she describes the distress they experienced because of the use of new technologies such as ECMO and LVADs that were creating liminal states between life and death. Dzeng (2017) describes how these physicians reported feeling unprepared to deal with these situations both clinically and ethically, and that “this uncertainty further contributes to moral distress” (p.23). I suggest that this acknowledgement of the uncertainty surrounding end-of-life care and medical prognostication should extend to a greater awareness that ethical decisions based on such clinical uncertainty are likely to involve moral uncertainty, and uncertainty can itself be a cause of moral distress.

Some authors suggest that acknowledging uncertainty and perceiving moral distress as a sign of uncertainty can help teams to reach agreement. Reflecting on a clinical ethics case, April and April (2016) suggest that had they “approached our patient’s sad case through the traditional frame of moral distress, we might have concluded that we were certain the right choice was to respect the patient’s autonomy and minimize further harm” (p.26). However, they suggest that because they viewed their feelings of moral distress with a broader view (as suggested by Campbell et al. (2016)), they were able to approach the case as one of “moral disagreement among sincere and well-intentioned stakeholders” (p.27), rather than as a case of “the moral white knight who alone knows the right choice and struggles bravely against others” (p.26).

Similarly, Johnstone and Hutchinson (2015) argue that Jameton’s conception shuts down communication by encouraging the “assumed rightness of nurses’ moral judgements” (p.8) thus undermining the process of moral deliberation. Rather than encouraging engagement in moral discussion, the narrow conception of moral distress potentially perpetuates nurses’ belief that their moral judgements are correct and justified and that other healthcare professionals are simply arbitrarily disagreeing with them. This has the potential to simply increase anger and resentment between healthcare professionals and erode relationships. Whereas, if it is acknowledged that nurses and other healthcare professionals also experience moral distress when they feel torn, conflicted and uncertain then, as April and April (2016) suggest, this could help to bring clinicians together. It seems that there are benefits therefore to

embracing uncertainty and divorcing moral distress from ‘knowledge of the right thing’, as April and April (2016) felt that accepting uncertainty reduced barriers between healthcare professionals, allowing them to come to a joint decision.

Furthermore, Haidt (2003) suggests that anger is a negative moral emotion that has a narrowing effect that closes individuals off from others’ viewpoints, whereas positive moral emotions have a broadening effect that can make individuals more open to new ideas, new relationships and new possibilities. In Table 12, I charted the emotions that seemed to predominantly occur with each moral event and found that amongst this group of participants, anger seemed to be the predominant emotion expressed during constraint, tension and conflict, all of which were more commonly associated with a feeling of knowing the right thing. If it was acknowledged that moral distress occurs during a broader range of moral events and encompasses a range of emotions, then this could, as April and April (2016) found, help to break down barriers between clinicians. In combination with environmental and institutional changes this could help encourage dialogue between healthcare professionals so that as a team they can recognise the complexity of moral decision-making and reach moral decisions together thus increasing the potential for moral communities to grow. Indeed, April and April (2016) believe a broader understanding of moral distress helped them to foster the mutual understanding required to reach consensus.

Thirdly, in a recent green paper, Batho and Pitton (2018) argue ‘knowledge of the right course of action’ sets an ‘epistemic threshold’ that is too high for moral

distress. They suggest, as I have found, that it is entirely plausible the moral agent experiencing moral distress may feel indeterminate about the morally appropriate action, or even fail to even see the options available to her. Indeed, I suggested in chapter 3 that a newly qualified nurse who feels angry/frustrated/upset/torn when caring for a HIV positive patient who had not shared their diagnosis with their wife may feel moral distress. The nurse may not recognise the cause of her distress, or even be able to identify the moral options available to her but, nonetheless, it still seems plausible to suggest that she feels moral distress.

Batho and Pitton (2018) suggest that an account of moral distress should avoid both this ‘epistemic threshold’ and the ‘objectivity constraint’: that the agent must be aware of all the options available to her. They suggest that many previous accounts of moral distress fail to recognise that moral distress “is primarily a function of how the world appears to the individual, which may be different from how the world objectively happens to be” and that moral distress shouldn’t depend on “the world actually being as she understands it to be” (Batho and Pitton, 2018, p.7). Indeed, moral distress is a unique phenomenon which is both caused and experienced differently by individuals. We ought to trust individual experiences of moral distress to inform the concept, as only they can provide an account of how the world appears to be to them: only a broad definition can capture these unique, individual experiences. I conclude therefore that moral judgement in the strictest sense ought to be jettisoned as neither a necessary nor sufficient condition of moral distress.

Although I am drawing this conclusion from the empirical findings of this study, combined with data and argument from empirical and theoretical literature, it is still important to note the limitations of this sample. Although the interviews were in-depth and provided rich data, the sample size was relatively small. All participants were European and only one participant was from a minority background. All participants lived in large multi-cultural cities. No participants expressed their own religious beliefs, although some participants did express an understanding that this might affect others moral beliefs. One of the limitations of qualitative research is the transferability of findings as the number of participants is sacrificed to achieve depth of analysis. This inevitably places limitations on the representativeness of one's sample. It could be argued therefore that this particular sample may have represented a group more comfortable with moral subjectivity and value pluralism which made them less likely to align themselves with objective beliefs. Indeed, many participants readily expressed the belief that there is no objective right or wrong and they seemed entirely comfortable with that. In the following quotation, Kayleigh discusses how ethical decisions are a very grey area, Elizabeth says there is not a right answer and Phoebe suggests nothing is black and white.

“... yes okay sometimes they may wake up to a certain aspect, people may cling on to every little think like 'but they're blinking' but that's a reflex. I don't know it's difficult, it's a very grey area.” (Kayleigh) (first presented chapter 5, section 5.3.2)

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“...And then you've got that decision that you've come to the feeling that it's wrong to be doing what you're doing but then you feel like it's kind of wrong to be making that decision because you're not making it, like you're making it from a place of very educated guessing but it's still like that small percentage of guess work in there and you're just like there is no right answer ...” (Elizabeth) (first presented, chapter 5, section 5.2.2)

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“As with everything in Intensive Care, nothing is ever black and white as much as I would like it to be....” (Phoebe) (first presented, chapter 5, section 5.2.2)

Many participants expressed an appreciation for moral pluralism and openly acknowledged that whilst respecting and honoring individuals’ moral values could make moral decision-making difficult, it was vital for providing patient-centered holistic care. Participants discussed feeling open to learning from others’ moral standpoints and found solace in knowing they could learn from engaging in discussion with others, as articulated by Freddie in the next quotation. Participants therefore seemed comfortable with moral subjectivity, whereas moral uncertainty seemed to cause moral distress.

***“I think it [moral distress] makes you challenge your own opinions and your own like, oh have I been thinking the wrong thing for so long and it probably, and I think it makes you more, it can change your view on some things like, and it can show you like the importance of things, like that, both, like the first situation showed like the importance of trying to get your opinion across. Um, or um, the second one about family engagement and then, but I think it can challenge your opinions on actual your practice as well. Like oh maybe we should try this for a bit longer and things like that.” (Freddie)
(first presentation of data)***

Another consideration is whether the nurses in this UK study were reluctant to form moral judgements because they may have lacked confidence regarding their knowledge of ethics and may have felt less empowered than participants from other studies. Many participants expressed feeling they had received little to no ethics education and so lacked the confidence and skills to make moral decisions, as Elizabeth expresses in the next quotation.

“I have not had a course in ethics, I did not study philosophy I’m not sure if I’m equipped. And I think that’s really scary and there’s quite a lot of distress that comes out of that, it’s like I’m not sure if I’m really equipped to make these decision or be part of the team that makes these decisions yet here. I am at the age of [early twenties] watching or helping someone to die and that - that’s your job and that’s what you do and it does seem very odd. I think that’s, I’ve kind of wondered that a lot in my career and just like I am, I – I’m you know that whole thing with nurses like you’re an angel it’s like no I’m not...I do not feel like I’ve got the sufficient like moral muscle to really like thrash this decision out like all the time.”
(Elizabeth) (from chapter 5, section 5.3.3)

Further research is required that explores the connection between moral judgements and moral distress in different contexts, cultures and environments to shed light on these differences.

Nonetheless, even if this sample were found to be particularly morally pluralistic, I have provided good practical reasons regarding why embracing uncertainty may be beneficial for healthcare teams that must work together to reach moral agreement. Furthermore, even if the findings in this study are doubted, there are other empirical and theoretical studies that continue to support the conclusion that moral judgement is neither necessary nor sufficient for moral distress to occur.

(iii) What about moral integrity?

In chapter 3 when reviewing the literature, I found that some authors had attempted to explain the concept of moral distress by suggesting that it occurs when one’s moral integrity is violated (see AACN (2006); CNA (2008); Hamric (2014) definitions in Table 9, and Thomas and McCullough (2015)). Suggesting that compromised integrity is the defining feature of moral distress allows authors to avoid the conclusion that the moral agent knows with certainty the

right thing to do because the terminology is vague enough to capture a breadth of situations; it also allows them to retain the spirit of Jameton's original conception by suggesting constrained moral agency is central. However, I am reluctant to use an ill-defined concept such as integrity to try and bring conceptual clarity because it only defers the problem.

My primary reason for including this challenge is due to a green paper published in the UK in February 2018 by Batho and Pitton (2018). In a larger project exploring the ethics of powerlessness, they analysed experiences that had been presented as moral distress in the existing literature, and they “endorse the claim ...that central to moral distress is the experience of loss of moral integrity” (p.15). They use seven accounts of moral distress as case studies to explore the key features and to determine what moral distress is. They suggest that an account of moral distress needs to avoid four problems, the first two I have already mentioned – the ‘epistemic threshold’ and the ‘objectivity constraint’. The other two being ‘absent affectivity’: the failure to incorporate feelings of distress into a definition of moral distress, and ‘narrow aetiology’: narrowly focusing on cases in which the individual is suffering from institutional constraints. Batho and Pitton (2018) use a phenomenological method to guide their exploration of moral distress and following their analysis, they conclude that in cases of moral distress, “an individual feels morally compromised by a situation S when she takes it that she was unable to be herself in S, because she should have been (but was not) able to do the right thing in S” (Batho and Pitton, 2018, p.17). This seems however to describe an affective feeling associated with moral distress rather than illuminating the circumstances in which it arises,

therefore saying little about the antecedents or consequences.

They suggest that the notion of integrity is unclear and therefore focus on the feeling of compromise, suggesting that this can help to “address the lacuna” concerning moral integrity (Batho and Pitton, 2018, p.15). They argue that in all seven cases studies, the healthcare professionals articulated distress because they felt in some way compromised as a person. However, there are two key problems with this account. Firstly, it is unclear what is meant by feeling compromised as a person and this account again seems to defer the problem. Secondly, their account can be challenged due to some significant methodological issues. Firstly, in all seven accounts, the moral agents describe situations in which they believe a moral wrong occurred. Secondly, the authors do not describe how they selected their accounts and upon exploring their sources, it can be concluded that they are not representative and do not provide a broad spectrum of moral distress experiences. The selection of their sources seems to frame moral distress in a specific way and this may have biased their conception of moral distress. One case was taken from a website (www.consciencelaws.org) which is concerned with protecting healthcare professionals conscience. On the first page of the website, it states: “The Protection of Conscience Project supports health care workers who want to provide the best care for their patients without violating their own personal and professional integrity”. Case study 7 is taken from a paper by Hardingham (2004) who also framed moral distress in terms of moral integrity, and three cases were taken from a special issue of a bioethics journal edited by a prominent US moral distress scholar who has also framed moral distress in

terms of compromised moral integrity. Therefore, their method of case analysis is not naïve phenomenological inquiry as they suggest it is, and instead the case studies can be seen to preempt their findings. Batho and Pitton (2018) have not provided a convincing argument regarding how a ‘feeling of being compromised’ clarifies moral distress and instead seem to have again deferred the problem.

My secondary reason for not including integrity into my suggested definition is because the participants did not frame their experiences in this way. The data does not therefore provide any mandate to frame moral distress in these terms. The actual word ‘integrity’ was only said once amongst all 21 participants and even when reviewing themes that could potentially relate to integrity such as ‘conscience’ or ‘moral compass’ these were only mentioned by 3 participants one or two times. The theme that potentially bears the most similarities to integrity is that of personal/professional values and responsibilities. However, again, when participants discussed feeling conflicted or constrained, they framed these experiences in terms of responsibilities and values, not integrity. This suggests that amongst this group of UK nurses, experiencing moral distress did not necessarily entail a violation of moral integrity.

Finally, I suggest that framing compromise in this way perpetuates the belief that compromise itself is bad. Batho and Pitton (2018) suggest that feeling compromised suggests an individual is both a perpetrator and a victim because they were unable to fulfil their deeply held beliefs. However, the ability to set one’s own values aside is often the key to achieving compromise. Reflecting on

an experience shared by Max, he discussed feeling morally distressed because he was uncertain about whether he agreed with the decision to withdraw life-sustaining treatment from a patient who was awake and had decided he wanted the IABP that was sustaining his cardiac output to be removed. Max may have felt very strongly that this was the wrong thing to do, and participating in this may have made him feel compromised as a person. However, this does not mean that the decision is morally wrong for the patient. There is a very difficult balance that needs to be struck in healthcare between healthcare professionals protecting and honouring their own values and beliefs, whilst also remaining cognisant that professionals have a duty of care and responsibility to patients. Framing compromise of one's values in the way Batho and Pitton (2018) propose seems to suggest that compromise itself is bad. An unwillingness to compromise one's own values may make one more inflexible and reluctant to engage in the moral compromise that is often required in healthcare. Indeed, we can see how this delicate scale has recently been tipped with the Trump administrations plans to expand healthcare professionals right to refuse medical services on the ground of religious or moral beliefs. Many commentators are worried that this will disproportionately affect the LGBTQI+ community and that this contravenes rights to access medical treatment (The Hastings Center, 2018). This may be an extreme example but the point is that feeling compromised, or engaging in compromise, doesn't necessarily entail that a moral wrong is being carried out.

When faced with having to choose a course of action in response to a moral problem, sometimes the only way to move forward is through compromise,

whether this is a compromise with others, or a setting aside of one's own values.

As Huxtable (2012) has argued:

“[C]omplexity and uncertainty, both in the realm of values and in the realm of facts (as far as these can be separated), are at the centre of the case for compromise. But so too are inadequate resources and the inability to honour every competing value, coupled with a prudent desire to ensure that one's values are voiced, an ongoing relationship with one's moral opponents and the need to reach a decision on a contested issue. The circumstances are ripe for compromise when such features are present in sufficient number or scale. The achievement of a principled compromise presumes communication and negotiation between the positions available and their respective defenders.
(p140-1)”

Framed in this way, compromise can be seen as a positive by-product of moral decision-making rather than inevitably causing distress. As Ives (2014) argues elsewhere:

“[E]mbracing compromise... ..points us back towards the pragmatic nature of the bioethical endeavour. Striving for coherence [in our ethical judgements] requires us to find the most [ethically] coherent picture we can – whilst accepting that perfect coherence may be unattainable. Embracing compromise requires us to accept that the

world is messy, with messy problems, and necessarily messy solutions.

(p. 310)”

By reframing compromise in this way and disassociating it from moral distress, this could also help to encourage moral communities to grow. Rather than healthcare professionals engaging in conflict with the aim of avoiding compromise in order to maintain one’s integrity, individuals could instead come together with compromise as their aim.

As I have discussed in previous sections, participants in this study were not always certain or steadfast in their ethical decisions. Some participants seemed to suggest they were open to discussion and possible compromise, as Chloe indicates in the next quotation.

“Even if you take two nurses who have had the same amount of time in ITU, worked in the same ITU, had the same experiences, looked after the same patients, I might say, ‘I think we should stop,’ and someone else might say, ‘I think we should carry on,’ or vice versa. I might say, ‘No, it’s not time yet. They’re too young. Let’s keep going.’ ... So, I don’t know. It’s hard. I think in my head it’s black and white and that’s my moral judgment, but then everybody is so different that I suppose you could put two people next to each other and they’d be completely different. So, no, maybe there isn’t a right or wrong answer.” (Chloe)
(first presentation of data)

I suggest that excluding integrity from the definition of moral distress is a pragmatic and coherent conclusion in line with the method of reflexive balancing. It is justified because integrity did not emerge as a finding in the empirical data, it is coherent because the inclusion of integrity provides no further conceptual clarification, and it is pragmatic because it paves the way for

recognising that compromise between healthcare professionals, families and patients may sometimes be a good thing.

7.3 The Moral Distress Model

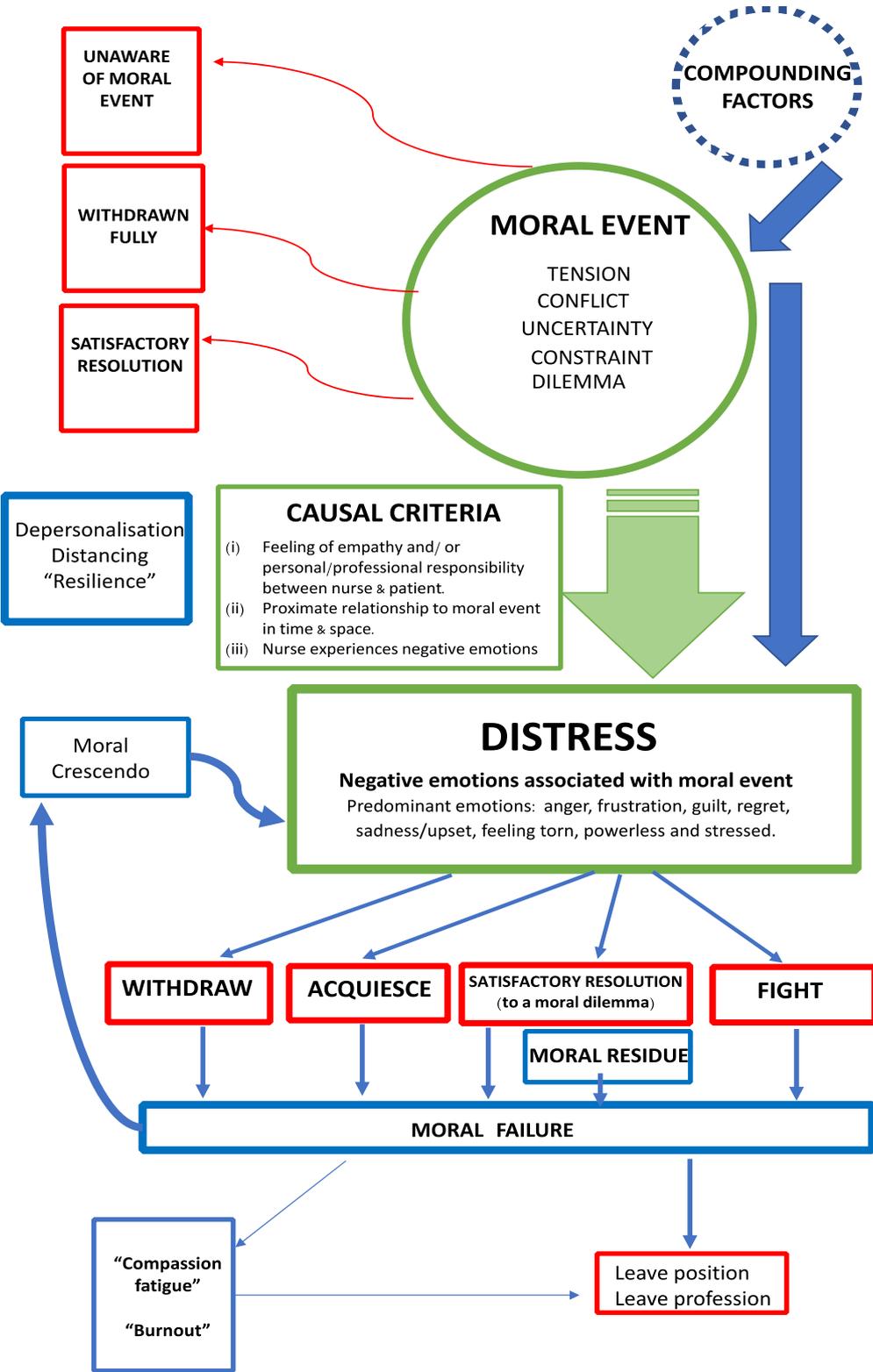
Now that I have addressed what I suggest are the most significant challenges to my definition of moral distress, I will describe the moral distress Model that I have developed. The model captures the definition of moral distress, compounding factors, responses to moral distress and the interaction of moral distress to other related concepts. As I have already discussed the other aspects of the model, I will focus here upon explaining the responses to moral distress and its relation to other concepts.

I analysed the data according to Van Manen's (1990) six activities for interpretive phenomenology.³⁰ This process of data analysis requires in-depth exploration of individual lived experiences, recorded and transcribed, the transcription is then coded line-by-line and shared experiences developed into themes. This means the data is broken down into individual lived experiences and then gradually built back up into shared themes to try and capture the phenomenon. The final two steps involve maintaining a strong and orientated relation to the phenomenon and balancing the research context by considering the parts and the whole. With these last two activities in mind I developed a mind map around the key elements of the phenomenon of moral distress and this became the moral distress Model. Paley (2017) argues that models such as these are useful for ensuring the researcher is moving from a description or

³⁰ This process is described in section 4.4.4

interpretation of the phenomenon to an explanation of it. As the phenomenological method I followed was hermeneutic, this process also helps to position the phenomenon back into the world. Heidegger argued that to reach true understanding of phenomena we need to understand it within the context of 'being in the world' (Heidegger, 1962). Therefore, whilst this model is a reduction of a complex phenomenon into its constituent parts, it also positions moral distress within the world, which "restores the contextual and existing meaningfulness of the world" (Heinonen, 2015, p.40). Developing this model was an iterative process, with multiple versions drafted, challenged and refined (in keeping with reflexive balancing). Many of the revisions were a result of challenges to the coherence of the model following conversations with the supervisory team, experts in the field of moral distress and bioethics, and healthcare professionals.

Figure 7: The Moral Distress Model



7.3.1 Responses to Moral Distress

Participants indicated four possible responses to experiences of moral distress: withdraw, fight, satisfactory resolution and acquiesce. There also seemed to be three possible responses that did not result in moral distress, which I will also discuss in this section. The responses to moral distress are in red boxes in the model.

(i) Withdraw

Some participants seemed to suggest that after repeated exposure to moral issues and failed attempts to change the outcome or impact decision-making they slowly began to withdraw. Withdrawal seemed to be active, whereas acquiescence, which I will discuss later, seemed to be more passive. Holly actively withdrew herself through avoidance behaviour and depersonalisation. In the next quotation, Holly discusses avoiding one patient whose care she believed was futile and refers to the patient as *“that”*. Other participants described patients as *“corpses”* that were *“dead already”*.

*“Because I can, like, I can raise it and so they’ll go oh, yeah, well Holly thinks that and then that’s it. Doesn’t change. You know, it goes on for weeks like that, and so...that’s, then you have avoidance behaviour. You wanna avoid a stressful situation. I don’t wanna be in that room with her. I can’t look after that and, you know, I don’t put on the waterworks, like, I’m in tears because I feel so strongly I can’t do it...”. (Holly)
(first presentation of data)*

Holly’s distress seemed to be created because she felt constrained- having to care for a patient whose care she believed was futile – she recognised that in an attempt to manage her moral distress she started avoiding the patient and felt she was failing to fulfil her duties and this created further guilt.

GM: “So, you said earlier that you sort of felt ashamed that you didn’t wanna go back into the side room.”

***Holly: “Yeah, kind of, ‘cos, you, you’re like I’m the [more senior nurse], I should be able to look after anyone in any situation, you know, you’re sort of a personal expectation is a sense of failure that you’re like, well, I can’t. I can be in there but what use am I?”
(first presentation of data)***

Isabelle also describes very consciously distancing herself by concentrating on the technical equipment and practical tasks to forget about the patient she was nursing. By distancing herself, Isabelle seemed to think she could limit the negative emotions associated with moral distress. Participants seemed to be trying to break or weaken the causal connection between themselves and the moral event – by distancing themselves emotionally thus reducing feelings of empathy, or focusing their professional responsibilities on the technical tasks-to reduce their emotional response. Although they could try and suppress feelings of empathy and personal responsibility, they remained connected because of their sense of professional responsibility and the need to fulfil their nursing tasks.

***“I didn’t ask too many questions, I didn’t want to get to know them too much, I just felt it was already very difficult. Like you know you sort of withdraw because you know there is only so much you can handle, I could feel that I couldn’t take very much already for some reason and I didn’t want to build too much of a relationship with them. Like I remember hearing that music trying to sort out the machine and not wanting to, like looking away from that wishing they could turn the telephone off, not show me the telephone like I don’t want to see that picture, I don’t want to hear that music. I know this is awful but you’ve got to focus on the equipment and I guess I was too busy to think much about the actual patient but that’s, to be honest that’s what saved me that day; I was busy enough not to think too much because I just felt like there was too much emotion in that bed-space. It’s awful, really awful when you think about it, like it’s not many people you do say these things to because it sounds like you’re driven by the equipment and nothing else like you don’t care for the person, the human being but I remember thinking this is the only way to handle this for me at the particular moment.” (Isabelle)
(first presentation of data)***

Peter and Liaschenko (2004) have also discussed the perilous nature of proximity, suggesting that whilst proximity to the patient can call the nurse to act, it can also cause them to turn away when they are unable to fulfil their moral responsibilities. This culminates in feelings of moral failure that I discuss later in this section.

On the left-hand side of the model, I suggest that some moral agents may be involved in an event but could be ‘withdrawn fully’ and therefore not experience moral distress. These nurses have broken the causal criteria possibly because they are so shut down from their feelings of empathy and sense of personal or professional responsibility that they conduct their duties without becoming emotionally involved. None of the participants in this study seemed to be fully withdrawn, and this is unsurprising considering they were a self-selected group of participants discussing moral distress. However, the possibility that some nurses could be fully withdrawn can be interpreted in the data. In section 5.4.2, I highlighted the importance of empathy with quotations from Elizabeth and Rebecca in which they both mentioned working with colleagues that they perceived as no longer caring. These individuals may be less likely to experience moral distress.

In the quotations below, Phoebe and Elizabeth discuss the belief that moral distress has some positive aspects, in particular they highlight how experiencing moral distress shows they still care and are connected to their patients. This supports the point made by Nyholm (2016) that I mentioned in the previous section regarding recognising that moral distress is a morally good response to

an ethically troubling situation. Significantly, both participants felt they learned important lessons from their moral distress experiences.

“I guess it laid the groundwork for me to start becoming more confident to speak to the doctors about stuff that I didn't feel we were perhaps doing right.... I was getting more confident just in general but I think that was one of probably the situations that made me think okay you need to know a little bit more about why we didn't withdraw sooner and you need to be thinking about that more and questioning that more. So, I think from that point of view going forward it definitely made me more that kind of nurse.... I definitely wouldn't be the nurse that I am today without all of those things happening, without seeing how badly it can be done and knowing I don't want to be like that from seeing how there is still one nurse at X Hospital that I just think is amazing and she will always be the person that I would work towards being like and then there's a whole group of nurses that I know I never want to be like that, and the same with doctors. ... it definitely had a negative effect at the time but I think going forward you have to be able to spin a positive on that and I have taken that as I will never let that happen again. I will do this, this and this to make sure it doesn't and I won't be like that, I will be like this, if that makes sense.” (Phoebe)

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“...it shows that you care on a level I mean yeah I would say that especially with ...yeah because you're distressed because your don't feel 100% confident in something that has happened, if you didn't feel distressed because you didn't care then you'd just be rubbish like, you'd be terrible, you'd be like oh well nothing could have been done. Or even if nothing could have been done I think it's a knee jerk reaction of a human person, I guess it's harnessing that and being like well if you feel distressed because of this if you can then make, if you can learn something from it or like talk it through then you feel like you did make the right decision or even that you didn't but then you kind of get why. Like if you can make something come out of it, if you can make a more confident decision next time it comes along then that distress like it's served a purpose, it drove you to that.” (Elizabeth)
(first presentation of data)

Although participants could appreciate some positive points, they still emphasised the negative aspects of their moral distress experiences. Eleven of the 21 participants discussed leaving either their current role or the profession. They cited several factors that were impacting their decisions but for many of

them, their moral distress experiences made up part of their rationale. It is important therefore that nurses can recognise, before it is too late, the point at which moral distress becomes too much so they can seek support.

(ii) Acquiesce

The second response to moral distress is to simply acquiesce. This is a mid-point between withdrawal and satisfactory resolution. The moral agent is aware of the moral event and they feel distressed but they simply accept the outcome without protest. In the next quotation, Rebecca seems to be rather passively withdrawing herself by fading into the background, almost trying to dismiss the moral event. Whereas withdrawal seemed to be more of an active process in which participants consciously tried to distance themselves.

“There are times when you feel something needs doing and you just carry on because you're carrying on. Again, that really depends on the consultants. We have got some who on the ward rounds will say ‘carry on with this because of this; look out for this and if this happens tell me’ and you know some of them will explain things a lot more than others but, for the most part they just say carry on because that's what we do essentially, we just keep people... and I understand a lot of the time there is a reason behind it or it's just resting before we you know but sometimes it's why are we doing this particular thing?”
(Rebecca) (first presentation of data)

a) Compassion Fatigue

The literature on compassion fatigue (CF) seems to mirror the moral distress literature: disparate, multiple and conflicting definitions, multiple empirical studies lacking conceptual consistency and a quantitative tool purporting to measure CF but which many are critical of (Nolte et al., 2017, Sinclair et al., 2017b). Although I have suggested in the moral distress model that moral distress seems to result in CF, it is difficult to determine whether participants

were experiencing CF because of the lack of conceptual consistency. I tentatively suggest that CF can be understood as “an acute onset of physical and emotional responses that culminate in a decrease in compassionate feelings towards others because of an individual’s occupation” (Sinclair et al., 2017, p.10). Indeed, both Chloe and Rachel discuss very consciously and purposefully trying to put up barriers to harden themselves and reduce their feelings of compassion and empathy for patients and families.

“I think I have a way of sort of blocking it out...our job isn’t an easy job and you have to be able to build walls in places where you suppose you probably wouldn’t really want them. Otherwise you’d spend all day in a bed space crying. There’s not – like this is where I say I think my level of sympathy and empathy might have – not gotten less but hardened up, because I can’t stand next to a patient’s bed and cry to a consultant and say, ‘This patient shouldn’t be alive. Why are you doing this?’ cause that’s not the right way to go about it.” (Chloe)

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“...your level of experiencing rubbish, horrible, horrible things we experience as ITU nurses, that’s really high level isn’t it. We see it all day, day in day out and so probably empathy is a lot less than it would be if we didn’t see that all the time but I think it’s a natural progression you can’t help. If you got so emotional about every single small thing you would never be able to do the job that you do, you would just fall apart, you just wouldn’t be able to do it, you would have to leave because you’d be an emotional wreck, you wouldn’t be able to do your job.” (Rachel)
(first presentation of data)

As with Holly and Isabelle, Chloe and Rachel seemed to be actively trying to distance themselves. They didn’t seem to think this reduced the quality of the care they provided but instead was a necessary protective measure allowing them to survive in ICU.

Whether these experiences constitute CF may be questioned and the causal relationship between moral distress and CF is certainly unclear. Ledoux (2015)

suggests that nurses may experience moral distress due to CF as they struggle to fulfil their professional obligations of providing compassion patient-centred care. Whilst this seems like a perfectly plausible suggestion, the nurses in this study didn't seem distressed by their reduced ability to empathise with patients but rather saw it as necessary to fulfil their professional obligations, suggesting CF is a by-product of moral distress. Neither did CF did seem to be an undesired by-product of moral distress, but rather a technique purposefully used in an attempt to reduce moral distress. This could be due to reporting bias; the participants may not have wanted to admit they lacked compassion because of possible stigma, especially considering the recent emphasis on compassion in nursing following the Francis Report.

Notably however, in the quotations presented here participants don't use the word compassion but rather 'empathy' and 'sympathy'. Indeed, Sinclair et al. (2017b) warn against conflating compassion with other emotions such as sympathy and empathy, and argue that CF cannot be fully empirically investigated until we have an understanding of compassion. It could be therefore that these participants were not experiencing CF but were trying to break the causal pathway between the moral event and distress by minimising feelings of empathy. Participants also seemed to understand this hardening process as 'resilience' and so in the model, I have placed this along the causal pathway. I discuss this in more detail in the next section.

Nonetheless, participants seemed to be putting up mental barriers to protect themselves from intimate relationships and emotional attachments in order to

decrease their distress. This seems to be another form of distancing and the correlation between moral distress, reduced feelings of empathy and possible CF is an area which requires further study.

b) Burnout

Some participants explicitly self-identified as burnt out and burnout is another phenomenon that has been associated with CF and moral distress (Rushton et al., 2015; Sinclair et al., 2017b). Burnout seems most often to be understood according to Maslach et al. (1997) as a “psychological syndrome of emotional exhaustion, depersonalization, and reduced personal accomplishment that can occur among individuals who work with other people in some capacity” (p.192); and is frequently measured using the Maslach Burnout Inventory. According to these three dimensions burnout can manifest as “an overwhelming exhaustion, feelings of cynicism and detachment from the job, and a sense of ineffectiveness and lack of accomplishment.” (Maslach and Leiter, 2016, p.103). In the burnout literature, depersonalisation is a symptom of burnout.

As I have discussed, depersonalisation seemed to be a form of distancing used by participants as a coping mechanism for moral distress and possibly indicates CF. Importantly, however, burnout can be differentiated from moral distress because a moral event or catalyst is not necessary (but may be present) for burnout to occur. For example, in the next quotation, Phoebe describes how the nursing staff on her unit reached a point of overwhelming exhaustion and feelings of ineffectiveness and cynicism. Isabelle also discusses an

accumulation of factors that caused her to feel burnt out, look for other jobs and even seek mental health support.

“...there was a lot of anger on the Unit and things like that because they felt utterly and completely abandoned. There were no matrons... everyone else was sitting at home and one nurse, one of my team, was quoted as saying "how bad does it have to get for someone to come in and help us?" and that's awful...” (Phoebe)

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“I talked to one friend about it in depth and that's it really and I, for some reason with lots of other factors, I just had a burn out last June and when I went through therapy I think that was one of the things that just, and I still feel emotional talking about it to be honest....I looked for other jobs actually. It was the fact that it was a nightshift as well. I didn't sleep very well, I was losing my sleep and all of that so it was not just that but I felt, the following month I felt so bad. I wasn't coping with things in general so that I did look for other jobs. So, I guess my practice was affected in that respect. I didn't want to be there, I didn't like my work. I was feeling grim about things in general like work and then life I guess as well, so I did look for other jobs. I did get another job and actually I think it was at the point where I started to work through things and then I realised I do like this job I don't want to leave it.” (Isabelle)
(first presentation of data)

It is interesting that participants were able to self-identify as burnt out and I suggest this could be due to the popularity of the topic in the nursing literature and mainstream media. It is a term that is very easy to understand and adopt. It also highlights the power of being able to diagnose and label one's own experiences. For Isabelle, it meant she could identify feeling that she was reaching a crisis point and seek support which prevented her from leaving her job. This provides another justification for broadening our understanding of moral distress as it means that the participants who framed moral distress as feeling torn and uncertain about the right thing may be able to label their experiences and start to understand them.

(iii) Fight

A third response to moral distress was the determination to fight and engage in moral issues. These participants, as mentioned in the previous section, saw value in their moral distress experiences as a learning opportunity and were determined to improve their practice. For example, Max described his concerns that a patient was entering the dying phase, he felt moral distress because he worried that the continuation of perceived aggressive care was wrong. After his shift, he went home and considered his options, the next day he spoke to a senior nurse who helped him raise his concerns with the medical team who reviewed the plan of care. For Max, his moral distress signalled a moral problem that he was able to effectively address and this experience made him feel confident he could act similarly in the future. Of course, had Max's concerns been disregarded, this may have increased his feelings of moral distress. This highlights the importance of dealing with moral problems as a team in order to mitigate moral distress.

"I'm glad that I spoke up. It's given me confidence to know that I would do that in the future if I felt that way again so I'm happy that I did it and that my concerns were taken sensibly; I wasn't dismissed or I wasn't told that I was acting out of place so I'm pleased that I was listened to by my senior peers and that it was taken up sensibly by the consultant and that he acted upon it and it wasn't just dismissed by 'oh the patient's dying... blah, blah, blah...' which you can get sometimes, you know we can say something and it's dismissed and it makes you feel inadequate if they do that. ...it's taught me a lesson about raising concerns and so no it's not 'all's well that ends well' I think the situation was resolved and I was satisfied with the resolution that the consultant made by assessing his capacity, it's taught me a lesson about being an advocate for my patient and having the confidence to do that so I think it's resolved in my head but I wouldn't say it was all's well that ends well because it wasn't, it wasn't a very pleasant situation to be involved in or to feel I was involved in." (Max)

(first presentation of data)

In the final excerpt from my reflexive research diary, I reflect upon the potentially positive aspects of moral distress and how these considerations fed into the development of the moral distress model.

Box 5: Reflexivity (4)

As a nurse who had experienced moral distress, I was very resistant to the idea that moral distress could ever be viewed as an inevitable and potentially beneficial part of moral life. I felt that any acceptance of this would curtail researchers or policy-makers from a commitment to addressing the effects of moral distress. I am thankful to Daniel Tigard, a doctoral student that I met at a conference, for debating this with me and challenging my views. Early into the data collection phase, I was surprised that participants were also articulating their view that moral distress was a valuable and inevitable part of nursing. Participants stressed that although their moral distress experiences had in themselves been deeply troubling and negative, they could now reflect upon their experiences and see them as valuable. Their experiences had challenged their assumptions and opinions, and helped them to learn and grown as nurses. Importantly, participants also discussed how their experiences illuminated their empathy and humanity. They never wanted to become uncaring and uncompassionate nurses and their suffering proved they were still connected to their patients. This finding helped me to construct the Moral Distress Model as it provided a possible explanatory factor regarding why some nurses didn't seem to experience moral distress or were less troubled by it: they were perhaps disconnected from their patients and therefore able to detach themselves.

a) Resilience

Resilience was a specific word used by some participants. As with burnout, I suggest this may be due to the popularity of the concept in the nursing literature and mainstream media. However, participants used the concept in an interesting way as they seemed to align resilience with distancing and depersonalisation. For example, both Natasha and Amelia associated resilience with withdrawing themselves to avoid deep emotional connections.

“I think it's weird but over your time as a nurse you build up a resilience and you adjust yourself so that you don't have that emotional connection with people sometimes whereas definitely when I was a student nurse I found things much more emotional and harder to deal with.” (Natasha)

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“...you do become very immune to but families' pain and you cannot give your whole heart to everybody because I don't think you would be able to live. You couldn't go home; you would stay in the hospital all day because you would retain nothing for yourself. And I think there is something about resilience it's you give what you can but you know to keep something back for yourself, to keep yourself strong and to keep yourself able to carry on and to come back in the next day. Because you have to, number one because it's your job but because these people need you and so you have to be resilient in a way that they don't have to be...because their family member is in a critical state. So yeah, it's keeping something back for yourself...because you can't nurture someone if you haven't nurtured yourself. You have to take care of yourself first to stay healthy and strong. I think recognising that, I think that's what resilience is. I just think you see too many things to not build that resilience. I think everyone has it in their own way and I don't know how other people do it. I only know how I take care of myself.” (Amelia)
(first presentation of data)

Resilience, in the context of nursing, is usually conceived as something that allows the nurse to engage and restore their caring relationships with patients. For example, Jackson et al. (2007) refer to resilience as the “ability of an individual to adjust to adversity, maintain equilibrium, retain some sense of

control over their environment, and continue to move on in a positive manner” (p.3). Participants certainly seemed to view resilience as a tool to enable them to regain some control and continue with their professional obligations but it did not allow them to deepen or strengthen their relationships. Rather ‘being resilient’ involved them distancing themselves from deep emotional involvement, which they seemed to perceive as ultimately for the good because it allowed them to continue in their role. Depersonalisation, distancing, dampening of one’s emotions were all perceived by participants as protective mechanisms against the emotional challenges of moral distress, and some participants constructed resilience in this way.

(iv) Satisfactory Resolution

Participants also discussed feeling the negative emotions associated with moral distress even when they believed the right thing had happened and a satisfactory resolution had been reached. I suggest that in these circumstances it is because although a satisfactory resolution was reached, it was a solution to a moral dilemma which meant they experienced the lingering feelings of guilt and regret associated with moral residue. In the following quotations, Beth and Amelia discuss feeling they did the right thing by withdrawing life-sustaining treatment from patients. However, they both suggest that despite feeling it was morally right, they felt morally uncertain (moral event) and felt guilt, regret and sadness (moral distress). These feeling’s continued to linger, Amelia states “*I still think about it, it’s not left me*” and these enduring emotions of guilt, regret and upset seem to signal moral residue because they experienced the moral event as a moral dilemma. Moral residue seems therefore to be a type of moral distress

that is predominantly experienced as lingering feelings of upset, regret and guilt which continue after moral distress.

“I have to do it and I know that I have listened to her and I am telling her, ‘We have heard you, we are hearing you, we are doing everything we can to get this process going, underway, we are doing this, we are doing that, we are doing this, so it’s not that I am not listening to you but we have to do this right and in the meantime, I need to look after you.’ But she still didn’t want me to. So, it was the guilt that I felt like I was hurting her, even though I knew we were right in the process of what we were doing and it had to be done that way but when I am standing right in front of her and doing these things with her... I could see her distress and that she was so upset and it just made me feel guilty. No matter how right I knew I was on a practical level, you know, seeing how it made her feel, it just, made me feel guilty.” (Beth) (from chapter 5, section 5.3.5)

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“...but I think that even though I think of it as a good day, I still think about it, it’s not left me. I still think about the fact that I ended a person’s life. I just think that there’s no way to get around that is there? It’s like, it was a good thing and I did it for the right reasons but it’s still a thing that I did and I’ve never done that before. It was an intentional thing. I intentionally ended a person’s life and when you say it like that...how can those words come out of my mouth? I just don’t think that’s an experience that many people have, and then to have to...to have to reconcile it, so with normal morals...hospital morals I guess...maybe its two different things. I just think it’s shocking. It’s a shocking thing.” (Amelia) (from chapter 5, section 5.2.5)

However, these emotions may not always occur. On the top left hand side of the moral distress model, I suggest three alternative reactions to a moral event in which moral distress does not result. Firstly, being ‘withdrawn fully’ which I discussed in section i (p.328). Second, where a ‘satisfactory resolution’ has been reached and it not followed by moral residue (suggesting that the moral event was not experienced as a moral dilemma). Third, moral distress may not be experienced because a nurse may simply not be aware of the moral event. I must emphasise that both ‘withdrawn fully’ and ‘unaware of moral event’ are hypothesised because they were not described by participants. In the case of lack of awareness, it is unlikely one would experience distress associated with

the event, given that they weren't even aware of it. Similarly, Christen and Katsarov (2016) suggest that moral sensitivity is likely to be a precursor to moral distress because, they argue, a certain level of ethical awareness is needed to recognise (1) that you are responsible within a certain context and (2) the moral salience of that context. If a feeling of moral responsibility is required for ethical awareness then this further supports my suggestion that personal/professional responsibility is part of the causal chain required for distress to be regarded as moral distress. Christen and Katsarov (2016) propose that individuals may intentionally become less morally sensitive as a way to reduce their moral distress. It is not clear exactly how one could do this intentionally, but this seems worthy of further exploration.

a) The Crescendo Effect

Epstein and Hamric (2009) suggest that moral distress leaves a 'moral residue' such that after repeated experiences of moral distress, one's feelings of distress, rather than return to baseline, accumulate - creating a crescendo effect over time. Epstein and Hamric (2009) use 'moral residue' differently to me (outlined in the previous section). Rather than residue being the result of experiencing a moral dilemma they characterise it as the "lingering feelings after a morally problematic situation has passed". Disagreement over labelling aside, there was evidence in the data that these experiences having a cumulative effect. Again, it wasn't a concept explicitly discussed or evidenced directly by participants, but it can be theorised from the findings. Many participants spoke about anticipating a point at which they would not be able to face the moral and

emotional challenges of their work and would need to leave their role, or the profession.

“I think that there’s only so long you can feel like this and then either you, you put up barriers and you think that, ‘This is normal, this is a normal way to treat people’, or you leave. And that’s why ICU nursing has such a high turnover because people can’t cope with the, the sadness. And the fact that I think a lot of the time people feel like they, the nursing staff aren’t listened to and that we are sort of not like pushing for withdrawal or you know, end-of-life care but we, we clearly see things differently to the medical staff.” (Danielle) (first presentation of data)

The potential for cumulative moral distress supports the idea that eventually individuals may reach a tipping point at which they leave the profession. To prevent this from happening, we need to recognise the signs of moral distress before nurses feel they can no longer cope.

b) Moral Failure

A final concept that I have incorporated into the moral distress model is from Tessman (2015) who argues that because we face non-negotiable moral requirements and moral dilemmas, the demands of morality are so great that moral failure is inevitable and inescapable.³¹ This concept was not explicitly mentioned by participants, but many participants seemed to suggest - due to the complexity of ICU – that not only was moral distress inevitable, but so was a feeling of moral failure. In the next quotation, Isabelle describes the pain, guilt and regret associated with trying to do what she believed to be the right thing.

³¹ To accept this notion of moral failure, one must also accept the existence of genuine moral dilemmas.

“... if it was the right thing why does it feel so hard and so painful, because often if you do the right thing you go home satisfied thinking I have done what I am supposed to do which is on many days working in ICU that is what you are going to get often, you leave and even if it's a little thing you think okay I have done this and this and this and that's great. That day was probably the worst day where I didn't feel like I had done the right thing and looking back I am convinced it was the right thing, it just did not feel like that and for a long time it still didn't feel like that.”

Isabelle (from chapter 5, section 5.2.4)

Isabelle describes how this experience made her feel *“like I left a part of me in that side room that day... or like it left a scar on me that I am never going to forget”*. It left irreversible damage. Isabelle in fact sought mental health support after this experience, and highlights the deep emotional impact some moral events can have on nurses and the need to provide adequate psychological support.

Tessman (2015) argues that in moral failure there can be no (full) recovery and that these failures call for normative theorising that goes beyond action-guidance because “there are no adequate acts to recommend” (p.179). She argues that “in such cases I want to be able to formulate a normative or evaluative claim that simply expresses this inadequacy without pretending that it could be fixed” (Tessman, 2015, p.179). I have argued elsewhere that one possible response to the distress that may come with these feelings is by reframing ethics learning. Rather than focusing upon finding the ‘right’ or ‘best’ solution, we should teach nurses and healthcare professionals that solutions are likely to be, and feel, messy and unsatisfactory (Morley and Ives, 2017).

7.4 Limitations

7.4.1 Sample

There are limitations to the sample that may affect the transferability of the findings. Although the interviews were in-depth and provided rich data, the sample size was relatively small. All participants were European and only one participant was from a minority background. Nurses from different cultures, contexts and backgrounds may have reported their moral distress experiences differently and may experience different emotional responses. However, because I suggest that ‘distress’ should be understood as an umbrella emotion, this does allow for a variety of different responses and therefore the definition I suggest may still apply. Three participants self-identified as male, and the rest female, therefore the gender ratio is less than the average number of men working in the NHS, at 14%, compared to 23% nationally (NHS Employers., 2017). To increase the representativeness of the sample, the project would have benefited from more male and more diverse participants. Due to the location of the recruitment sites, all the participants lived in large multi-cultural cities and none of the participants expressed their own religious beliefs, although some participants did express an understanding that this might affect others moral beliefs.

7.4.2 Interpretation

The findings I have presented are based upon my interpretation of participants reported experiences, and therefore if my interpretations are fallible, then so are my conclusions. I have tried to maintain trustworthiness in this process by

carefully explaining my interpretation of participants' experiences and provide verbatim quotations to support my interpretations. By including excerpts from my reflexive research diary, I hope to have highlighted to the reader the time I took to challenge and question my interpretations to try and ensure they fairly and accurately represented participants' experiences.

Paley (2017) is critical of qualitative researchers for using terms such as 'many' or 'most' participants because he argues that these are quantitative terms. Paley's criticism is not of generalising *per se* but rather of the polarisation between qualitative vs. quantitative research methods. Indeed, this emphasises a tension that I first discussed in chapter 4 between what is unique and what is shared. In both phenomenology and feminist research, the aim is to try and build common themes through shared experiences and this does require some generalisation. However, one must always be aware of the risk that any generalisation can contribute to the oppression of those whose experiences that do not 'fit'. As Jaggar (2000) states, "contemporary feminists have learned to be more modest in their use of 'we', and they see no self-evident answer to the question of what are 'our' best practices of moral inquiry" (p.464). With this in mind, I do not claim that this conception of moral distress will resonate with all nurses, nor that all nurses will feel the force and effects of the power structure I have painted in the same way.

7.4.3 Methodological Considerations

Empirical bioethics is a developing field and requires the use of different methods and methodologies. The methodology for this project is complex, but

I have been careful to try and explain how each element can be regarded as not only coherent but necessary. Each method(ology) was selected on the basis that it provided the right tools, techniques and as Scully (2010) calls them, ‘biases’ to carry out this project. The empirical bioethics method of reflexive balancing has thus far only been used by its author. As Ives (2014) suggests, the process of reflexive balancing is not significantly different to the way in which a philosopher would present her argument and defend it against criticism. Whilst the process is in many ways intuitive, it has been a challenge to make the process transparent, to make clear my boundary principles and normative recommendations.

7.5 Conclusion

Within this chapter, I have presented three potentially damaging challenges to the definition of moral distress that I have developed. To each of these challenges, I provided pragmatic, justifiable and coherent responses regarding why this broader definition ought to be adopted within the UK nursing context. I also presented and described the moral distress model which shows the commonly described responses to moral distress and the relationship of moral distress to other related concepts.

CHAPTER 8 – RECOMMENDATIONS

8.1 Recommendations for Practice

Participants discussed a number of different support systems that they sought in order to try and manage their feelings of psychological distress that arose due to moral events. However, accessing these support systems wasn't always straightforward. In the following, I suggest ways that access to these could be improved:

1. One participant discussed accessing the Employee Assistance Programme and felt that it was a useful resource. However, most participants seemed either unaware of this existing support system or when highlighted to them, reported feeling that it was not an appropriate resource. Reducing the stigma of accessing these services, raising awareness of their availability and purpose, and highlighting that they are an appropriate resource to use for feelings of psychological distress might encourage nurses to access them.
2. Participants from one site had attended Morbidity and Mortality meetings primarily because they wanted to understand why certain plans of care had been carried out. The purpose of these meetings is, however, to discuss deaths retrospectively and they are often attended primarily by surgeons and consultants. One participant reported engaging in conflict during a meeting and therefore these meetings didn't seem to provide a safe space for dialogue. Furthermore, because it is a retrospective meeting about a patient death, this may not be an appropriate time to question previous decisions.

3. Some participants attended Schwartz Rounds to engage in dialogue with other healthcare professionals. Again, participants reported wanting to understand why certain plans of care had been carried out. Participants reported feeling these were useful for opening-up dialogue, expressing their emotions and connecting with other healthcare professionals. Indeed, a recent longitudinal study found Schwartz Rounds resulted in a statistically significant improvement in staff psychological well-being (Maben et al., 2018). However, participants reported attending in their own (unpaid) time because they could not attend when on shift and reported they were not well advertised. To allow staff the opportunity to discuss the psychological distress that arises due to their involvement in moral events, protected time needs to be created so that nurses can attend.
4. Some participants attended debriefs and found these useful as a safe space to share their perspective regarding incidents. However, they only occurred very sporadically and often only in response to patient deaths. Some participants felt that even if problems were raised during debriefs, they were never resolved. I suggest that debriefs should occur routinely and not only in response to patient deaths but also other challenging circumstances. These would provide a time to discuss any concerns that nurses may have regarding patient care that could then be raised (by senior nurses if necessary) with the medical team. Additionally, when debriefs do occur and problems are raised, action plans should be formulated and resolutions reported back to staff. Awareness that issues

are being addressed may help to mitigate nurses' feelings of powerlessness and reduce their moral distress.

5. Safe reflective spaces such as clinical supervision may enable nurses to discuss and process the psychological distress that they experience due to moral distress.

Interventions and support mechanisms for moral events:

1. A small number of participants reported seeking ethics support from the legal team, the chaplain, the ECMO team and palliative care. No other ethics support systems were identified. Most participants identified consultants as the ethical decision-maker and some questioned the legitimacy of this. This suggests that some nurses do seek clinical ethics guidance for ethical problems and an identified resource could to help them manage moral events.
2. One site does have an active clinical ethics committee (CEC) but none of the participants discussed using this as a resource or seemed aware of it. Where CECs are present, staff members need to be aware of them and feel able to make referrals so they can seek clinical ethics advice for support to manage moral events.
3. I have argued elsewhere (Morley, 2016a) that the NHS might benefit by learning from the US system where it is a requirement for hospitals to have a mechanism for healthcare professionals to resolve and educate employees regarding ethical issues concerning patient care (Caulfield, 2007). In the UK, there is no requirement for Trusts to have a CEC and although they are becoming more prevalent, they are not mandatory,

healthcare professionals attend in their own (unpaid) time and institutional support varies (Slowther et al., 2012). There is some evidence to suggest that CECs may improve quality of care as agents of systematic change (McClimans et al., 2012).

4. There is evidence in the US which suggests clinical ethics support services help healthcare professionals manage the moral events which cause psychological distress, and moral distress. Wocial et al. (2010b) reported that unit-based ethics conversations helped nurses to prepare for ethically challenging situations by reducing their feelings of powerlessness and that a nurse ethicist could provide an important link between bedside nurses, the clinical ethics committee and senior leadership (Wocial et al., 2010a). Clinical ethics support services such as CECs, unit-based clinical ethics conversations and dedicated nurse ethicists may help to foster communication and decision-making amongst healthcare professionals which my findings suggest can serve to exacerbate moral events. By making moral events easier to manage and ensuring nurses voices are heard, feelings of distress may be reduced.
5. Most participants reported feeling their ethics education had been insufficient and they did not feel prepared to manage the ethical challenges they faced in practice. Nurses need to be better prepared to face ethical challenges in order to enter into moral discussions in the clinical area. As Wocial et al. (2010a) found, feeling better prepared to manage moral events and associated negative emotions may help nurses to feel more empowered and able to engage in moral discussion, thus

making moral events easier to manage and reduce their feelings of powerlessness.

8.2 Recommendations for Policy

It is notable that many participants in this study discussed their intentions to leave either ICU or nursing altogether. They cited different reasons but many participants explicitly stated that they felt too much of an emotional burden from ICU and many related this back to their moral distress experiences. For example, four participants had chosen to reduce their hours doing bedside nursing, one participant was moving to another area due to her moral distress experiences and another intended to move into palliative care because of her experiences related to perceived futile and aggressive care. ICU is an area that is particularly transitory within nursing, as many nurses want to get experience working in this high acuity area. However, whilst ICU may continue to have a high turnover for these reasons, many nurses report intention to leave due to traumatic and stressful experiences, and poor working relationships (Khan et al., 2018). To retain nurses in ICU and to support them both psychologically and ethically, I suggest that responses to moral distress need to be integrated at the policy level:

1. The Canadian Nurses Association, the American Nurses Association and the American Association of Critical Care Nurses have published position statements regarding moral distress and the need to take action to mitigate its effects and support critical care nurse. As a first step, similar UK organisations such as the BAACN, RCN and NMC should also publish position statements highlighting the need to address moral

distress. This would help to highlight moral distress as a legitimate problem and alert NHS Trusts to the need to implement and make accessible the recommendations suggested in the previous section.

2. More generally, the NMC should look at improving educational standards and competencies regarding clinical ethics so that nurses feel better prepared to deal with ethical challenges in practice. This could in turn mean they would feel more empowered to engage in moral discussion with other healthcare professionals.
3. More broadly still, politicians need to recognise not only the importance of nurses and the need for safe staffing for patient safety but also recognise the emotional burden nurses bear. By implementing and funding resources that support nurses ethically and psychologically in clinical practice, NHS Trust may reduce intention to leave. Furthermore, this would show that they value the work that nurses do.

8.3 Recommendations for Further Research

Through conducting this project, a number of areas for further research that require further exploration are suggested:

1. Further research could be conducted to see whether this broader definition resonates with nurses in other contexts and cultures.
2. If this broader definition is accepted, more research is required to explore the types of interventions that can help to address moral distress.

I suggest that interventions may be more effective if they are targeted at the sub-categories of moral distress such as moral-constraint distress, moral-conflict distress and so forth.

3. Participants reported feeling moral distress due to moral uncertainty and they discussed lacking confidence to make moral judgements. I questioned whether the participants in this study were particularly morally pluralistic and whether this affected their willingness to form judgements. Further research could explore what factors impact nurses' ability and willingness to make moral judgements, and whether improvements in ethics education could empower nurses to make judgement and participate in moral discussion.
4. Further research could explore the role of empathy, aiming to identify what it means to be empathetic, opposed to compassionate and sympathetic, and whether more empathetic individuals are more likely to experience moral distress.
5. Related to the previous point, further research could explore whether moral sensitivity is related to moral distress and whether it can be said to be a precondition for moral distress.
6. The question of whether the psychological distress experienced by participants should be deemed 'moral emotions' arose as a possible area of enquiry.
7. In order to try and establish the causal relationship between moral distress and CF, there needs to be consensus regarding what experiencing CF means. Once CF is defined, further research can be conducted regarding how and to what extent CF and moral distress are related.

8.4 Recommendations for Education

A number of recommendations for the education of nurses and other healthcare professionals are suggested:

1. Participants discussed feeling they lacked adequate knowledge of ethics to formulate moral judgements and contribute to discussions and decision-making. Pre-and post registration nurses would benefit from greater access to ethics education to help them manage ethical issues in the workplace.
2. Participants discussed feeling they lacked the confidence to manage ethical problems in the clinical area and, at times, this prevented them from raising their concerns or engaging in ethical discussions. Nurses need to have the confidence to engage in these discussions and to contribute their knowledge and skills. A greater awareness of not only ethical theories and principles, but also skills in working through and coming to ethical decisions, could empower nurses to engage in moral discussions and in turn mitigate feelings of moral distress. Greater access to ethics education that is case based could help nurses better understand how ethics functions in clinical scenarios. The aim of working through case based scenarios could be not only to identify the morally preferable action, but also to highlight that morality is messy and ‘solutions’ are often difficult to find. As I have argued elsewhere, this could help nurses prepare themselves for often inevitable feelings of moral distress, moral residue and moral failure (Morley and Ives, 2017).

3. Whilst some participants were aware of the specialist holistic knowledge they possessed about patients' and families' wishes and desires (often by virtue of spending long hours at the bedside), other participants failed to see the importance of this information, labelling it, for example, the "fluffy" stuff. To contribute meaningfully and effectively to clinical-ethical decision-making, nurses need to be aware of the value and relevance of their knowledge, and this begins with education. Such education might draw on approaches to ethical decision-making such as the 'Four Quadrants' approach by Jonsen et al. (2006), which highlights the holistic nature of ethics, and value of different kinds of knowledge, by encouraging decision makers to consider medical indications, patient preferences, quality of life and contextual features. Clinicians could benefit from continuing post-qualification inter-professional education that is case based and focused on helping them to resolve clinical-ethical issues. There have been advances in the use of simulation training for ethics education and I suggest this could be fruitful for further development (for example, Smith et al. (2013) and Lewis et al. (2016)).
4. It has been suggested that moral distress can act as a warning sign for ethical issues (Gallagher, reported in Morley, 2016), and one of the advantages of the broader conception that I advocate for is that moral distress can act as a warning sign for a wider range of moral problems. Pre- and post-registration nurses could be taught to recognise how moral distress signals the presence of an ethical issue, and the predominant emotions associated with each moral event (Table 12) could act as a guide for nurses and other healthcare professionals to recognise the

underlying moral problem, thus helping them develop an appropriate response.

5. Participants also discussed feeling they lacked confidence and knowledge regarding the law and how this affected ethical decision-making. This lack of knowledge seemed to cause increased moral uncertainty about the right thing to do and consequently moral distress. Pre-and post-registration nurses would benefit from more healthcare law education, which may give them the knowledge and confidence to engage in ethico-legal discussion.
6. Many of the ethical issues and narratives of moral distress described by participants could have been mitigated by improved communication, teamwork, respect and flattening of the hierarchy. All clinicians would likely benefit from increased pre-and post-registration inter-professional education that is focused on improving communication and respect amongst the different groups of professionals and encourages them to better understand one another's roles, responsibilities and values.

CHAPTER 9: CONCLUSION

9.1 Conclusion

Much of the previous research regarding moral distress has failed to fully explore and address the conceptual confusion that has surrounded the term since its introduction to the nursing literature. In recent years, there has been more attention to the concept using purely theoretical methods. However, this project provides a unique contribution because the account of moral distress is both theoretically and empirically informed. Using a feminist empirical bioethics methodology, I used the lived experiences of critical care nurses to provide an empirically informed account of moral distress that is sensitive to the UK nursing context, and to provide recommendations for how we ought to respond to it.

First, I conducted a narrative synthesis of the literature paying particular attention to the way in which moral distress has been defined and conceptualised within the previous empirical and theoretical literature. I highlighted the different definitions of moral distress and examined the ways in which the various necessary/sufficient conditions changed not only the circumstances in which moral distress is believed to occur but also the meaning of the concept itself. I concluded chapter 3, with a proposed working definition of moral distress that was to be refined in light of the empirical findings. I also raised a number of key questions that were left unanswered and these were used to inform data collection and analysis.

I chose a feminist empirical methodology that allowed me to focus on issues of

voice, power and relationships, and to treat nurses' experiences as epistemically valuable, allowing an understanding of moral distress from their perspective (Donchin and Purdy, 1999). Feminist interpretive phenomenology provided the methodological tools to collect and analyse the empirical data. Rather than focus purely on the causes of moral distress, interviews were exploratory and led by the participants' experiences. For some, the interviews seemed to serve as a kind of ethical awakening as it provided the time and space to reflect upon and discuss their moral experiences. Consequently, my interview method became more Socratic as I explored and probed participants' emotional responses, the circumstances in which the various emotions occurred and participants' moral beliefs and judgements, thus mirroring the 'philosophy seminar' style of questioning previously carried out by Alderson et al. (2002). I didn't challenge the validity of participants' moral experiences but rather investigated the circumstances in which their feelings of distress occurred, as they described a multitude of moral experiences that caused distress.

From participants' experiences, I found that not only did constraint cause 'distress', but also a number of other moral events (moral tension, moral conflict, moral dilemmas, moral uncertainty), therefore providing empirical evidence that supports previous theoretical arguments made by authors who have argued that the definition should be broadened (such as Fourie (2015) and Campbell et al., (2016)). In empirical bioethics, the aim of the researcher isn't to simply accept participants accounts but to maintain a 'critical stance' thus enabling the formation of normative conclusions (Code, 2002). Due to my feminist commitment to uncover and address oppressive practices, I grounded

my normative arguments with these values. I argued that denying these experiences as moral distress would be an act of testimonial and hermeneutic injustice, as participants' narratives would be disregarded and they would continue to struggle to make sense of their moral experiences and associated emotions. In North America, the concept has power and therefore allowing these participants to recognise their experiences as moral distress, is to treat them as legitimate and in need of a response. As Latham (2016) suggests, a broader understanding of moral distress actually motivates a broader range of responses because it has "important consequences for the normative debate about what, if anything, one is obligated to do about one's moral distress" (p. 31).

There will of course be objections to the suggestion that the definition ought to be broadened. I have tried to pre-empt these objections and I have used deviant cases from my own data to challenge my account of moral distress. For those that may argue moral distress (as described by Jameton (1984)) is a 'term of art' and that broadening the definition makes it analytically and diagnostically meaningless (Wocial, 2016; Epstein et al., 2016), I propose that we should understand moral distress as Fourie (2015) suggests: as subdivided into different forms of distress, such as 'moral-constraint distress' and 'moral-dilemma distress'. I argue that in fact this will enable us to develop and provide more targeted interventions for moral distress as each may require a slightly different response. For example, for moral-constraint distress, the moral agent may need to articulate their viewpoint and address the constraint preventing them from carrying out a particular action; whereas, for 'moral-dilemma

distress', the moral agent may need ethical guidance or time for reflection and discussion so they can decide which moral requirement to fulfil.

Importantly, I have suggested that broadening the definition may also have practical benefits as it may help to break down barriers between healthcare professionals. As Johnstone and Hutchinson (2015) argue, Jameton's conception shuts down communication by encouraging the "assumed rightness of nurses' moral judgements" (p.8). Rather than encouraging engagement in moral discussion, the narrow conception of moral distress potentially perpetuates nurses' belief that their moral judgements are correct and justified and that other healthcare professionals are simply arbitrarily disagreeing with them. This has the potential to increase anger and resentment between healthcare professionals and erode relationships. Whereas, if it is acknowledged that nurses and other healthcare professionals also experience moral distress when they feel torn, conflicted and uncertain then, as April and April (2016) suggest, this could help to bring clinicians together. It seems that there may be benefits therefore to embracing uncertainty and divorcing moral distress from 'knowledge of the right thing'.

From the findings, I also highlighted the predominant emotions that seemed to occur amongst this group of participants. Due to the unique qualities of individual experience and differences in cultures and contexts, I do not suggest that these are the only emotions that could occur due to a moral event but rather if an individual experiences a negative emotion that can be regarded as falling under the umbrella emotion of 'distress', and it is causally related to a moral

event, it should be regarded as ‘moral distress’. By identifying one’s predominant emotions, this may also help individuals to determine the cause of their distress and seek the most appropriate support mechanisms.

I was also able to identify compounding factors that seemed to exacerbate or mitigate moral distress, for example the power differentials between healthcare professionals, and epistemic norms and practices that affect decision-making. I suggest that whilst some of these are unavoidable (such as the need to make decisions), the way they are managed is avoidable (for example, discussing these decisions with the bedside nurse who is responsible for enacting them). Uncovering these practices can help guide individuals, teams and organisations to begin addressing moral distress. These compounding factors are likely to vary across institutions and amongst healthcare professionals but once identified they can be addressed and responded to.

Although the focus of this project has been nurses’ experiences, because the definition remains broad it is likely the conceptualisation will resonate with other healthcare professionals but the compounding factors will vary. This may require slightly different responses and support mechanisms, and I suggest that with this conceptualisation of moral distress as a starting point, this could be a further area of study.

Within this project, I have also provided an explanation regarding why some individuals experience moral distress and others do not. This is captured in the causal criteria which determines whether one’s distress ought to be regarded as

moral distress. Using the empirical data and tort law, I suggested that feelings of empathy and/or personal/professional responsibility meaningfully connect nurses to those involved in moral events and that breaking this causal chain may help to mitigate moral distress. However, I suggest that this may not be a desirable way to reduce moral distress but rather we should instead find ways to support nurses in clinical practice, as I have recommended in chapter 8.

Lastly, a unique contribution offered by this project is empirical evidence that suggests some individuals do see the value of moral distress. Some participants discussed their perception that moral distress signalled they still cared and were deeply connected to their patients. Nyholm (2016), Howe (2017) and Tigard (2017) have all suggested, in various ways, that moral distress may simply be a natural response to a morally troubling situation and that it may not be desirable to get rid of it. Indeed, there is a sense to which moral distress seems to act as an important warning sign for a moral issue. However, I caution against conclusions that suggest that because of this we need not act to reduce it. Although some participants could appreciate positive aspects of moral distress, they still overwhelmingly emphasised the negative aspects of their moral distress experiences. I conclude therefore that we must continue to address moral distress but with this broader conception in mind.

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Appendix 1: Data Extraction Guide

Data Extraction Guide (adapted from Popay et al. 2006)

Empirical papers:

Title of paper

Author(s)

Methodology

Clear statement of the aim(s)

Details of the data collection method: is the method suitable for the research goal?

Statistical methods used: suitable to the research design?

Qualitative methods: suitable to the stated methodology? Is there evidence of reflexivity?

Statistical results

Recruitment strategy: is the strategy appropriate for the research method/goals?

Method of data analysis provided: was this method rigorous? Was sufficient data presented to support the findings?

What definition of moral distress is used?

Does the definition cohere with data collection method?

Do the findings add to conceptual/theory development?

Theoretical papers:

Philosophical commitment stated/ implied

Philosophical strengths and weaknesses: strength of argument? Coherent with philosophical commitments previously stated?

Clear statement of findings: is the argument credible? Are the findings credible?

Conclusions: value of the research?

What definition of moral distress is used?

Does the definition cohere with data collection method?

Do the findings add to conceptual/theory development?

Exploring relationships within and between studies?

Are the theoretical conclusions supported by the empirical literature?

What are the relationships between studies (individual, methodologically grouped, empirical, theoretical)?

Are there similarities in research design?

Are there similarities in findings? If so, what are these similarities?

Are there differences in findings? If so, what are the differences?

Would a graphical tool, idea webbing or conceptual mapping help to illustrate these relationships?

Appendix 2: Quantitative Data Extraction Table

Reference	Setting	Study Aim	Sample	Data Collection Method	Key Findings	Strengths/ limitations of the study	Findings similar to which studies	Value of the research
Hamric & Blackhall (2007)	USA	To explore RNs & attending physicians perspectives of caring for dying patients in ICU with particular attention to moral distress, ethical climate, physician/ nurse collaboration, & satisfaction with quality of care.	Registered RNs ($n=196$); attending physicians ($n=29$) from 14 ICUs in 2 healthcare institutions. Site 1= rural hospital, no palliative care service (RNs $n=106$ and Drs $n=29$) participated. Site 2= urban hospital- only 4 Drs participated so data not analysed as unable to compare with nurse ($n=90$) data. Active palliative care service in site 2. Baseline characteristics fairly similar between RNs in site 1 & 2- but higher educational qualifications in site 2	2 focus groups (RNs $n=8$ & Drs $n=12$) for survey test & development. Survey using various instruments. Corley's original (1995 & 2001) MDS- reduced to 19-items post focus group. Cronbach $\alpha= 0.83$ for the shortened scale. Perception of ethical climate measured using McDaniels (1997) Ethical Environment Questionnaire (EEQ) (same tool in Corley et al. 2005) but shortened (26 to 15 items) Olson's HECS used in the second site (cost reasons cited)- so cross-site comparison of ethical climate not completed. Quality of care q's- 4 likert style statements to choose from. Collaboration measured using adapted scale by Hojat et al. (1999).	"Moral distress occurs when the practitioner feels certain of the ethical course of action but is constrained from taking that action" (p.423). SPSS version 11.0 for analysis. RNs experienced more moral distress ($p<0.001$). Same items on the MDS caused greatest moral distress. Intensity scores were similar for the 3 items but RNs scored higher in frequency. In site 2- 17% of RNs had left a position due to moral distress & 28% had considered it. RNs perceived ethical climate & collaboration more negatively than Drs. RNs that scored highly in moral distress, scored lower in ethical climate, satisfaction & collaboration scores.	Using the same instruments for both Drs & RNs that do not necessarily translate across professions. Multiple scales & tools used- coherence between them questionable as not used together before & also laborious for the participant who may be fatigued due to length of the survey. Wide variability in moral distress scores amongst RNs.	Distinguished between moral distress & moral dilemma. RNs had higher moral distress scores ($p<0.001$) and the same situations caused moral distress in RNs & Drs. as in Hamric et al., (2012). RNs perceived morally distressing situations as occurring more frequently ($p<0.001$). Top 2 most frequent moral distress items- same as Corley (1995), and Hamric et al. (2012)	Reinforces findings in Corley (1995), which are then replicated in Hamric et al. (2012) concerning most frequent moral distress items. Taken alone, the findings are not significant but together they have more power. Does not add to conceptual development, explores causes of moral distress, not included in the narrative synthesis.

Appendix 3: Qualitative Data Extraction Table

Reference	Setting	Study Aim	Sample	Data Collection Method	Key Findings	Strengths/ limitations of the study	Findings similar to which studies	Value of the research
Kälve­mark et al. (2004)	Sweden	To explore what situations healthcare professionals (healthcare professionals) involve ethical dilemmas and whether they cause moral distress.	Nurses, doctors, auxiliary nurses, medical secretaries and pharmacy staff	Focus groups in one cardiology, one heamatology and one pharmacy department in Stockholm. 5-7 healthcare professionals in each focus group representing the different professions. 2 researchers present- 1 moderator, 1 note-taker. Sessions last from 1.5-2 hours and were recorded & transcribed. The authors do not describe their data analysis techniques.	Moral distress redefined as: “Traditional negative stress symptoms, such as feelings of frustration, anger, and anxiety, which might lead to depressions, nightmares, headaches and feelings of worthlessness, that occur due to a conviction of what is ethically correct but institutional and structural constraints prevent the desired course of action.” (p.1077). Themes found: 1. Resources- lack of time/staff, lack of beds. 2. Rules vs. praxis- difficulty following policy, breaking rules voluntarily & being forced, justifying breaking rules. 3. Conflicts of interest- patients integrity, professional secrecy & relations, patients vs. colleagues. 4. Lack of supporting structures. Evidence against Jameton’s definition.	The authors accept Jameton’s distinction between moral distress, moral dilemmas and moral uncertainty. The authors do not describe their data analysis techniques. Themes supported by verbatim quotations.	One of their stated aims is to explore whether moral distress is limited to situations where the healthcare professional knows the ethically correct action but is constrained from taking it- Sporrong et al. (2005) developed a questionnaire for pharmacists from the results of this research.	The authors present evidence to dispute Jameton’s definition of moral distress, namely that agents do not necessarily have to be constrained to experience moral distress and that a dilemma can be present whilst moral distress is experienced. They propose two new definitions of moral distress- one at the beginning, which does not appear to be empirically rooted, and a second after the findings are presented. This research contributes to theory development & is included within the narrative synthesis.

Appendix 4: Theoretical Data Extraction Table

Reference	Aim	Method	Key Argument	Philosophical/ ethical commitments	Limitations/Strength of argument	Findings similar to which studies	Value of argument
Jameton (2013)	To discuss and extend the concept of moral distress beyond the healthcare setting and to the concept to climate change.	Conceptual analysis of moral distress.	Discusses evolution of concept of moral distress (MD)- represented the issues of power & inequality that nurses faced. Feminist ethics only encouraged passivity & regret, later replaced with assertiveness & call to speak out on behalf of profession. As other professions with their own ethical codes developed, it became evident MD wasn't just experienced by nurses. Climate change is an increasing ethical problem and those concerned about it experience moral distress- in terms of healthcare ethics, there is very little control over environmental ethics that can be exercised at the bedside. Bioethicists ought to move beyond the moral distress of clinical matters to global ethics.	Redefines MD as “a common experience in complex societies- arises when individuals have clear moral judgments about societal practices, but have difficulty in finding a venue in which to express concerns.” (p.297) “...MD expresses a decision point, a moment of emotive immobility, where ambivalence needs to be resolved toward a choice. Once the choice is made and action is undertaken, the psychological elements of distress tend to diminish.” (p. 303)- goes against Jameton’s previous definitions where a moral decision is a prerequisite for moral distress.	Jameton doesn't describe the basis for the newly suggested definition of MD. However much of his argument is not reliant upon accepting his definition but upon a more classic understanding of MD in which the agent knows the right thing but cannot carry it out, i.e. failing to prevent climate change is morally wrong but healthcare systems create huge amounts of environmental impact. Jameton argues for a movement beyond moral distress generated by clinical matters to concentrating on global environmental ethics.		The broadening of the definition of moral distress is interesting, especially in relation to climate change which is an ethical issues of huge importance. I question to what extent this concept has utility within climate change discussions. This is included in the synthesis because it is authored by Jameton and he appears at times to contradict his previous definition, in particular by stating that moral distress is a ‘decision-point’.

Appendix 5: Mixed Methods Data Extraction Table

Reference	Setting	Study Aim	Sample	Data Collection Method	Key Findings	Strengths/ limitations of the study	Findings similar to which studies	Value of the research
Varcoe et al. (2012)	Canada	To examine nurses' perceptions of moral distress & ethical climate, and situations they consider to be morally distressing. Their research question is "What are nurses' perceptions of and responses to moral distress?" (p.490).	Random sample from a database of RNs working in British Columbia, inclusion criteria= currently practicing in an acute care setting. nurse's (n=374) responded, RR 22%. (n=292), 78% provided responses to free text responses. Demographic data collected.	Corley's MDS (Corley et al. 2001 referenced but not clear if 32 or 38-item scale utilized) & Olson's Hospital Ethical Climate Survey (HECS), with 3 open-ended questions, asking for a description of a morally distressing situation, what action they took and the effect on patient care. Analysed the free text responses using interpretive description, reflexive process adopted with the team sharing reflective notes. NVivo 8 used for data management & coding themes.	Themes found in response to situation causing moral distress: workload/overload, lack of competency in self & others, witnessing unnecessary suffering, moral compromise, negative judgements about patients &/or families by providers. Denied any negative effects of moral distress on patients, believed they had mitigated the effects. In response to moral distress: participants described speaking to managers, calling Drs to change orders, arranging debriefs, promoting palliative care & pain control, consulting with professional bodies, ethics committees, encourage communication about DNAR status, incident reports, policy. They felt their actions were often dismissed & others felt they were overreacting. Others reported responsive actions to their concerns.	Their research question may have been better explored utilising a qualitative approach such as interviews, rather than using the MDS with 3 open ended questions. They could have gained more in depth responses by probing. However, evidence of rigorous qualitative approach in analyzing the open ended questions: data analysed as a team, with reflective notes. Very large sample size for qualitative responses.	Reference Jameton's (1984) definition, & Webster & Baylis: moral distress occurs "when one fails to pursue what one believes to be the right course of action (or fails to do so to one's satisfaction) for one or more of the following reasons: an error on judgment, some person failings (for example, a weakness or crimp in one's character such as a pattern of 'systemic avoidance'), or other circumstances truly beyond one's control. (p.218)" (p.489). Denial that moral distress affects patient care- also in Sauerland et al. (2014).	Do not provide analysis of the MDS or HECS. Analysis of open-ended questions presented but still limited by survey design. Furthermore moral distress was predefined at the beginning of the surveys. Similar causes of moral distress as found in other papers: Themes of overwork, lack of competency in self/ others- Silén et al. (2011), Corley et al. (2005), Rice et al. (2008). Limited to exploration of causes of moral distress and therefore will not be included in the narrative synthesis.

Appendix 6: Literature Review Data Extraction Table

Reference	Study Aim	Sample	Data Collection Method	Key Findings	Strengths/ limitations of the study	Findings similar to which studies	Value of the research
McCarthy & Gastmans (2015)	To examine the ways in which the concept of moral distress (MD) has been delineated & deployed in the argument-based nursing ethics literature. Focused questions: How is MD defined? Related concepts? Normative meaning of MD? Sources of MD? What is the impact of MD?	Argument-based nursing ethics literature. 20 papers analysed. Argument-based literature= articles that analyse concepts & present arguments to draw conclusions about the clinical conduct that nurses ought to undertake.	4-step method for systematic reviews developed by McCullough et al. (2004) and (2007). 1. Identifying focused questions. 2. Carrying out a literature search for articles that address one or more of the focused questions. 3. Evaluating the methodological adequacy of articles identified. 4. Identifying the position of the author in relation to the focused questions. Search strategy and terms provided.	Do not align themselves with one definition but instead explore the various definitions suggested by other authors. They describe 3 key issues: 1. Conceptualisation of MD- MD described as a ‘discrete entity’- a set of experiences characterised in psychological-emotional-physiological terms & more moral attributes such as integrity, values & beliefs. 2. Elements of constraint – most draw attention to external constraints that limit nurses’ ability to carry out their values/ beliefs. 3. View of moral agency- moral agent, who has made a moral judgement, as constrained.	Thoroughly explain the search strategy and replicable. Focus on conceptual issues rather than causes of moral distress, as in other reviews. Limited to argument-based literature, however, arguably this is a more neglected area of study & therefore a legitimate area of focus.		The authors review a number of definitions that have been suggested by previous authors in the argument-based literature, some of which I have highlighted in Table 6. This work is an important contribution to the literature because an analysis of conceptual development is presented, however the authors do not propose a new definition and instead call for further conceptual analysis to clarify the concept- for this reason the paper will not be included in the narrative synthesis.

Appendix 7: Papers Included in Narrative Synthesis

Reference, Setting, Study Design	Study Aim, Sample	Method	Key Findings/ Key Arguments
Allen et al. (2013), USA, quantitative	To measure moral distress among healthcare professionals (healthcare professionals) working in adult and paediatric settings, to explore differences between professions and demographic factors in relation to levels of moral distress. 1 healthcare system (4 adult acute, 2 district hospitals, 1 children's community hospital) Participants ($n=323$) recruited. RNs ($n=207$: 194 adult, 13 paediatric); advanced registered nurse practitioners (ARNPs) ($n=7$); physicians ($n=62$: 51 adult, 11 paediatric); social worker/ case manager ($n=27$); respiratory therapists ($n=20$).	Moral Distress Scale-Revised (MDS-R) from Hamric et al. (2012), 0-4 scale, 6 parallel versions for RNs, Drs, other healthcare professionals & adult & paediatric settings. Internal consistency- Cronbach α ranged from 0.88-0.95.	Moral distress defined similarly to Jameton (1984). Overall high levels of moral distress. ARNPs- highest mean moral distress scores, followed by respiratory therapists (RT). RNs & RTs -same 2 highest scoring moral distress items. Higher moral distress scores in adult setting compared to paediatric ($p=0.007$). Higher moral distress scores associated to those considering/ had considered leaving/ left a previous position due to moral distress ($p<0.001$).
Astbury et al. (2015), UK, theoretical	To determine whether there is scope to study moral distress in pharmacists.	Literature review, not systematic.	Moral distress defined according to Jameton (1984). Suggest moral distress occurs when individuals are prevented from exercising their moral agency and act in discordance with their moral judgements & values. Suggest that because pharmacists are evolving their role to include responsibility for optimal drug-therapy & patient focused care- there are more opportunities for ethical & moral problems to arise.

Barlem & Ramos, Brazil, theoretical	To formulate a theoretical model of moral distress to clarify the concept and to broaden the definition.	Theoretical.	New definition of moral distress suggested in which moral distress arises due to constraints on moral action, moral deliberation, moral sensitivity and advocacy, moral distress is connected to feelings of powerlessness and causes “ethical, political and advocational inexpressivity” and “physical, psychological and behavioural manifestations.”
Campbell et al. (2016), USA, theoretical	To motivate a broader understanding of moral distress and argue for a broader definition.	Theoretical, hypothetical case studies.	6 cases of distress that can be understood as moral distress: 1. Moral uncertainty. 2. Mild distress. 3. Delayed distress. 4. Moral dilemma. 5. Bad moral luck. 6. Distress by association. New suggested definition of moral distress: “one or more negative self-directed emotions or attitudes that arise in response to one’s perceived involvement in a situation that one perceives to be morally undesirable”.
Corley (1995), USA, quantitative	To measure levels of nurse moral distress using a newly developed instrument- the Moral Distress Scale (MDS). Members of the mid-Atlantic, American Association of Critical-Care Nurses ($n=111$).	32-item MDS, 1-7 scale, based on Jameton’s & Wilkinson’s conception of moral distress. Scale reviewed by 3 nursing ethics experts for content validity & test-retest reliability $r=0.86$ ($p<0.01$), Cronbachs $\alpha = 0.93$.	moral distress defined as “painful feelings &/or psychological disequilibrium caused by a situation in which (1) one believes one knows the ethically ideal action to take & (2) that one cannot carry out that action because of (3) institutionalized obstacles such as lack of time, lack of supervisory support, medical power, institutional policy, or legal limits” (p.280). Mean moral distress scores were below the mid-point suggesting low levels of moral distress. Most frequent: ‘Initiate dramatic life-saving actions when I think it only prolongs death’ (M=5.9; SD= 1.37). ‘Following the family’s wishes to continue life support even though it is not in the best interest of the patient’ (M=5.5; SD= 1.27). Greatest intensity of moral distress: Giving medication intravenously to a patient who had refused to take it orally’ and ‘Giving only haemodynamic stabilizing medication intravenously during a Code Blue with no compression or intubation.’ (no mean or SD provided). No significant findings between moral distress score & demographic factors.
Corley et al. (2005), USA, quantitative	To explore relationships between moral distress intensity & frequency, correlations to ethical work environment & demographic characteristics of nurses. RNs ($n=106$) from 2 large medical	Correlational study. Revised version of the Moral Distress Scale (MDS)- originally 32-items, now a 38-item questionnaire (0-6 scale) (problems identified in previous studies added: pain management, managed care &	Elaborates but references Jameton’s (1984) definition: “painful feelings and/or the psychological disequilibrium that occurs when nurses are conscious of the morally appropriate action a situation requires but cannot carry out that action because of institutionalized obstacles.”(p.382) Higher moral distress with lower perception of ethical climate. Lowest intensity item: ‘give medication

	centres, medical & surgical units. 62% response rate (RR).	incompetent healthcare professionals's). Measures moral distress frequency & intensity, Tool reviewed & revised by experts. Cronbach α for the revised MDS intensity scale=0.98 & MDS frequency scale= 0.90. Ethical Environment Questionnaire (EEQ) developed by McDaniel (1997) - 20-item questionnaire with 5-point style Likert scales. Cronbach α = 0.93.	intravenously during a code with no compressions or intubation.' Highest frequency: not stated. Lowest frequency: 'respond to patient's request for suicide assistance when the patient has a poor prognosis'. African Americans had higher moral distress scores- authors question whether less empowered.
Dzeng et al. (2016), USA, qualitative	moral distress emerged as a major theme when exploring physician & trainee views on resuscitation orders & end of life- this paper was produced in response to this finding. Qualified physicians carrying out further medical training ($n=22$) from 3 sites, participants selected based on a range of years of experience (1-6 years). Participants excluded if they had not attended medical school and residency (3-7 years, or more of continuing medical training in the US).	Qualitative in-depth interviews with an interview guide. 2 interviews conducted via Skype, all other conducted in person. Lasted 45- 120 mins, audiotaped, transcribed verbatim. Data collected until theoretical data saturation achieved. "Moral distress occurs when individuals believe they are unable to act in accordance with their ethical beliefs due to hierarchical or institutional constraints"- reference to & loosely based on Jameton's 1984 definition of moral distress.	Key themes with direct quotations to support: 1. Perceived futile end of life care-'torture' & causing 'suffering' 2. Practitioner suffering & emotional angst- due to providing perceived futile care. 3. Feelings of powerlessness- unable to terminate futile care. 4. Hierarchy- attributed their powerlessness to the hierarchy, trainees unable to question superiors. 5. Dehumanization & rationalization- distancing themselves from patients- describing patients as a 'body' not a 'person'. 6. Coping strategies- institutions that encourage conversations to reflect & share emotions, notify healthcare professionals involved about deaths.
Epstein & Hamric (2009), USA, theoretical	To propose a preliminary model- the "crescendo effect"-which describes the relationship between moral distress and moral residue.	Theoretical	Moral distress= initial distress- conflict of values. Moral residue= reactive distress- the psychological effects. moral distress is not the psychological effects- it is a purely ethical phenomenon. Psychological distress such as under-staffing does not violate core values as one can act on their ethical obligations still. Associating moral distress with psychological distress minimizes the experience to a mere psychological phenomenon, rather than ethical. The crescendo effect arises due to moral residue, which serves as a new baseline each time there is a new morally distressing situation- both moral distress and moral residue accumulate to a crescendo, which can cause healthcare professionals to leave their profession.

Fourie (2015), Switzerland, theoretical	To clarify the concept of moral distress.	Conceptual analysis with focus on Jameton's definition of moral distress from his 1993 paper.	Argue that Jameton's definition implies moral distress & moral dilemmas are mutually exclusive. Jameton fails to differentiate between a moral dilemma (in the strict, philosophical sense) and moral conflict, thereby amounting to the claim that moral distress & moral conflicts are mutually exclusive. Jameton's definition is compound (a 'narrow' definition) because the specific cause & response are built into the definition, making moral constraint a necessary condition of moral distress. Situations of moral uncertainty, moral dilemma & moral conflict are ruled out as causing moral distress. New definition suggested.
Hamric et al. (2012), USA, quantitative	To develop and test a revised version of Corley's MDS-the Moral Distress Scale-Revised (MDS-R). Aim of the MDS-R is to include more root causes of moral distress, expand its use outside of intensive care unit (ICU) & make it appropriate for other healthcare professionals. RNs ($n=169$: 131 adult, 38 paediatric) 48% RR. Physicians ($n=37$: 12 fellows, 8 residents, 17 attending physicians) 60% RR. From 8 ICUs: 6 adult, 2 paediatric from one academic medical centre in southeastern US.	MDS-R - MDS updated, shortened, re-worded, applicability broadened & space for 2 free-text responses- in consultation with Corley. 6 parallel versions developed for nurses, physicians, other healthcare professionals in adult & paediatric settings. 0-4 Likert scale, measures frequency & intensity, 21-items. Content validity performed with authors & doctoral prepared colleagues in nursing ethics. Cronbach $\alpha = 0.67$ for physician scale & 0.89 nurses. Shortened version of Olson's HECS Cronbach $\alpha = 0.77$ for physician scale & 0.87 nurses.	Pre-defined moral distress at start of the survey- definition not provided. Drs (Mean (M) 62.58; Standard Deviation (SD) 21.92) had significantly lower moral distress scores than RNs (M 91.53; SD 44.24) ($p < 0.0001$) but similar mean scores in perceptions of ethical climate- nurse (M 48.54; SD 8.27) Dr (M 52.13; SD 6.36). RNs & Drs agreed on 6/7 top situations to cause moral distress. Top 2 greatest frequency: 'Follow the family's wishes to continue life support even though I believe it is not in the best interest of the patient' & 'Initiate extensive lifesaving actions when I think they only prolong death.'
Hamric (2014), USA, theoretical/ case study	To analyse a case study that caused moral distress, identify themes and suggest strategies to reduce moral distress.	Case based discussion developed from the authors previous experiences working with morally distressed clinicians.	Moral distress consists of having one's moral values/ obligations compromised. Moral residue is lasting & powerful because action/inaction has resulted in threatening core beliefs & values that help define oneself. moral distress is subjective because everyone holds different beliefs. Presents a case of futile care & the effects on the healthcare team. moral distress permeates across 3 levels- individual, team/unit, institution/ organization. Emphasizes the importance of team communication, getting to the roots of the moral distress. New definition suggested.

Hanna (2004), USA, theoretical	To provide an overview of research related to moral distress.	Theoretical	Due to Jameton's 1984 definition- moral distress was explored as an occupational issue. However nurses more often speak about the psychological effects of moral distress- this reveals a mismatch between the experience of moral distress and his definition. Raises the issue of role morality and questions whether it is even possible to separate oneself in such a way. Hanna identifies 4 themes in current research (of note, the studies she looked at were mostly unpublished PhD & MSc dissertations). 1. Anguish or interior suffering. 2. Role Morality. 3. Truth telling 4. Conflict associated with early insights.
Hanna (2005), USA, qualitative	To discover the essence, properties & full-content domain of the concept of moral distress & to create a universal definition. Variation sampling to recruit RNs (<i>n=10</i>) who have assisted with legal, elective abortions. Screened participants prior to recruitment to ensure all had assisted with elective abortions & had experienced moral distress related to the procedure- although it is not stated how they pre-screened. Interviewed one nurse who had not experienced moral distress for comparison.	Semi-structured interview-guided by phenomenology & aspects of the Roy Adaptation Model (RAM) model of nursing- this work emphasizes the holistic unity of human persons. Conceptual basis for the study is verativity- the view humans are in a relationship with a loving Creator & universal truths are discoverable.	Moral distress defined as "an employer/employee conflict, whereby the employee knew the right thing to do, but was prevented by the employer from carrying it out."(p.96)- attributes this to Jameton 1984. 5 properties of moral distress are identified: 1.Perception. 2. Pain. 3. Valuing. 4. Altered participation. 5. Perspective. 3 types of moral distress identified: 1.Shocked. 2. Muted. 3. Suppressed (persistent).
Hardingham (2004), Canada, theoretical	To discuss the concepts of moral distress, moral integrity & moral residue in relation to nursing practice in Canada and to understand how ethical nursing practice can be strengthened.	Theoretical.	Moral integrity is necessary to a moral life and is relational in nature. When integrity is threatened moral distress & moral residue occur. Introduced philosopher (Larry May) interpretation of integrity- as coming to maturation through reflection, developing a critical coherence which is often done through socialization in a professional group. Advocacy can harm nurses because the organization have the power, not individual RNs- institutional barriers cause moral distress. Nurses are forced to go against their moral integrity & to change this there needs to be a change in the practice environment, organizational culture and education of nurses. Suggests building a moral community as an environment to practice ethically.

Jameton (1984), USA, theoretical	To describe the ethical issues in nursing practice.	Theoretical.	First introduction of moral distress to nursing practice. moral distress defined as occurring “when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (p.6). Distinguishes between moral distress, moral uncertainty and moral dilemmas- stating that moral & ethical problems in healthcare are of these 3 types.
Jameton (1993), USA, theoretical	No aim stated.	Theoretical.	Distinguishes between initial & reactive distress. Jameton redefines moral distress, argues his 1984 definition is initial moral distress and Wilkinson’s 1987/88 is reactive moral distress. Initial distress involves feelings of frustration, anger & anxiety when faced with institutional obstacles & disputes with others regarding values, and reactive distress occurs when one fails to act upon their initial distress. Many causes of moral distress are rooted in questions of moral responsibility- nurses have many options, but it is difficult to know which option to take- Jameton argues this engenders moral dilemmas, it is questions of moral responsibility, rather than moral dilemma that cause moral distress.
Jameton (2013), USA, theoretical	To discuss and extend the concept of moral distress beyond the healthcare setting and apply it to climate change.	Conceptual analysis of moral distress.	Discusses evolution of concept- argue it represented the issues of power & inequality that nurses faced. Feminist ethics only encouraged passivity & regret, later replaced with assertiveness & the call to speak out on behalf of their profession. As other professions with their own ethical codes developed, it became evident moral distress wasn’t just experienced by nurses but almost anyone working in an organization. Climate change is an increasing ethical problem and those concerned about it experience moral distress- there is very little control over environmental ethics that can be exercised at the bedside. Bioethicists ought to move beyond the moral distress of clinical matters to global ethics.
Johnstone & Hutchinson (2013),	To discuss the nature of moral distress and discuss the quality and safety of moral decision-making, moral conduct and moral outcomes in nursing and healthcare	Theoretical- using empirical research as evidence.	Moral distress is conceptually flawed, lacks an empirically robust foundation which although extensive, is methodologically weak & disparate. The hypothesis that moral distress occurs when nurses know the right thing is concerning for 3 reasons: 1. It assumes nurses know the right thing uncritically. 2. It is apologist & perpetuates the notion of nurses as

USA, theoretical			powerlessness. 3. It is question- begging- it takes for granted that moral distress is a “bona fide state” causally related to 1 and 2.
Kälvemark et al. (2004), Sweden, qualitative	To explore which situations involve ethical dilemmas and whether they cause moral distress for healthcare professionals (nurses, doctors, auxiliary nurses, medical secretaries and pharmacy staff).	Focus groups in 1 cardiology, 1 heamatology, 1 pharmacy department in Stockholm. 5-7 healthcare professionals in each focus group representing the different professions. 2 researchers present- 1 moderator, 1 note-taker. Sessions last from 1.5-2 hours, recorded & transcribed. The authors do not describe their data analysis techniques.	Moral distress redefined as: “Traditional negative stress symptoms, such as feelings of frustration, anger, and anxiety, which might lead to depressions, nightmares, headaches and feelings of worthlessness, that occur due to a conviction of what is ethically correct but institutional and structural constraints prevent the desired course of action.” (p.1077). Themes found: 1. Resources- lack of time/staff, lack of beds. 2. Rules vs. praxis- difficulty following policy, breaking rules voluntarily & being forced, justifying breaking rules. 3. Conflicts of interest- patients’ integrity, professional secrecy & relations, patients vs. colleagues. 4. Lack of supporting structures.
Maiden et al. (2011), USA, quantitative	To examine relationships between moral distress, compassion fatigue (CF) and perceptions about medication errors. Certified critical care nurses (CCRN) from members of the American Association of Critical-Care Nurses (ACCN) ($n=205$). 5 CCRNs working clinically also recruited to participate in one focus group.	MDS, 38-item scale, 0-6 scale. Cronbach $\alpha = 0.97$. The Professional Quality of Life Scale (ProQOL) - to measure CF, from Figley (1995), 30-item, 0-4 scale. Cronbach $\alpha = 0.81$. Medication Administration Error Survey, 77-item from Wakefield et al. (2005) to assess nurses’ perceptions of why medication errors occur, why they aren’t reported & an estimated percentage of actual errors reported. Focus group with 5 CCRNs to discuss medication errors, issues & feelings related to errors & resources to discuss.	Moral distress defined as an “individual knowing the correct course of action to take, but because of real or perceived institutional constraint or barrier it is impossible to carry out the correct course of action” (p.341) - provided as a direct quote from Jameton (1984). Moderate statistically significance found between moral distress and CF ($p<0.001$)- the more moral distress, the higher their perception of CF. CCRNs reporting intent to resign also reported higher mean CF scores. Higher level of moral distress associated with perception that lack of communication with physicians cause medication errors. Medication errors similar psychological feelings to moral distress, cause some CCRNs to consider leaving nursing.
McCarthy & Deady (2008), USA, theoretical	To reconsider the concept of moral distress.	Review of the literature, not systematic.	Moral distress not specifically defined, described as knowing the right thing to do but unable to do it, or doing what is believed to be the wrong thing. 2 concerns regarding the evolution of moral distress: 1) Currently it is an umbrella term, capturing the experiences of people who are morally constrained, internally & externally. However also concerned that research on moral distress lacks conceptual clarity & there is an overemphasis on the

			psychological components & not enough on the ethical. 2) Argue moral distress perpetuates negative meta-narratives of nurses suffering, powerless and ineffective in moral decision-making. Should not restrict research regarding moral distress to nurses alone.
Musto & Rodney (2009), Canada, theoretical	No stated aim.	Theoretical- critical realism (CR). Argue that critical realism provides the ideal method in which to further explore and understand moral distress. Quantitative and qualitative methods are limited as to what they can find and therefore reveal about moral distress. CR is concerned with ontology- to say something about a thing itself not beliefs, experiences or current knowledge.	There is a lack of conceptual clarity regarding moral distress definition, study & application. There needs to be revision of the epistemological assumptions underpinning knowledge & use of the concept. Critical issues with the concept: 1. the location of the moral distress (within the individual or within the structures of healthcare). 2. Jameton's definition links with action & inaction. Argue that we need to understand the interplay between individuals' actions & the structural context, which is rife with power dynamics; researchers commit 'epistemic fallacy' - conflate the concept with the measures to study it. Nurses do not always experience moral distress when there is a constraint preventing their moral judgement & therefore there must be more behind the concept. They suggest this could be contextual and suggest ontological study of moral distress.
Nathaniel (2006), USA, qualitative	To further elucidate the experiences & consequences of nurses' moral distress & to formulate a logical, systematic theory of moral distress & its consequences. This is presented as a newly developed grounded theory of moral reckoning in nursing. RNs (<i>n=21</i>), not stated where recruited but that the study was advertised in newsletters, a conference and shared with nurse leaders to advertise.	Grounded theory. Informal, unstructured interviews, not audio-recorded- field notes taken during & immediately after. Line by line coding. Concepts gathered. Constant comparison used to create theory from data. Feedback gained from participants once the theory was developed. Existing literature on moral distress used to inform theory development.	Moral distress defined as "Moral distress is pain affecting the mind, the body, or relationships that results from a patient care situation in which the nurse is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgment about the correct action, yet, as a result of real or perceived constraints, participates, either by act or omission, in a manner he or she perceives to be wrong." (p.421) moral distress did not emerge as a major theme instead 'moral reckoning' did- argues this moves beyond moral distress, explaining the processes of ease, resolution, & reflection- process of moral-decision making. Story-telling emerged as integral.
Peter & Liaschenko (2004),	To deepen the understanding of moral distress and moral ambiguity through a spatio-temporal analysis of proximity.	Theoretical argument with empirical literature to support.	Moral distress follows from the fact RNs are situated in a certain 'social space' in healthcare, situated in the nurse-patient relationship, which requires physical nearness. RNs have a sense of moral agency and identity for example in unsupportive environments where there is a lack of staffing and lack of

Canada, theoretical			recognition, this is threatened & moral distress results. Proximity to patients means RNs feel their moral responsibilities very acutely & consequently moral distress. There is moral ambiguity because it is not clear where RNs moral responsibilities begin & end.
Peter & Liaschenko (2013), Canada, theoretical	To explore the concept of moral distress in light of feminist theory.	Theoretical argument with empirical research to support.	Feminist theory offers insight into 3 core elements of moral agency: identities, relationships and responsibilities. moral distress is a reaction to the constraints on these 3 core elements. 1. moral distress threatens nurses' identity as virtuous caregivers. 2. moral distress represents failure to adhere to normative expectations, personally and institutionally. 3. Nurses responsibilities are enshrined in codes of professional ethics but unlike others, often the realizations of these are dependent on others. Close proximity to patients results in shared suffering and heightened moral distress. To reduce moral distress they encourage sharing one's values & responsibilities, repairing damaged identity with stories of resistance & a movement towards relief of suffering.
Peter et al. (2014), Canada, qualitative	To explore nurses' moral knowledge in cases of perceived overly aggressive care. Graduate RNs (<i>n</i> =15) from any area of clinical practice studying at one university invited. Inclusion criteria= those who experienced moral distress when caring for a patient receiving perceived overly aggressive care.	Critical narrative approach- participants asked to describe the situation in question. Did not define 'aggressive care' to allow for open responses. Narratives were audio recorded and transcribed. Narrative thematic analysis. Analysis and themes agreed upon within the research team- the dominant theme was used in creation of the typology. Audit trail utilized and reflexivity employed.	Moral distress defined according to Jameton (1984)-authors question what nurses 'know' to be the 'right thing to do.' 4 narratives identified: 1. 'Wait and see: medical uncertainty.' & importance of time to see if interventions work. 2. 'Deflected responsibilities to respond to dying, death or futility.'- focusing on cures & avoiding difficult conversations, delegating communication. 3. 'Divergent understanding, responsibilities, & temporalities.'- different faiths, views of familial responsibility & belief in alternative medicine. 4. 'Privileged medical understandings & responsibilities'-medical dominance & focus on cure prolongs aggressive care.
Redman & Fry (2000), USA, theoretical	To discuss what can be learned from nurses' ethical conflicts.	Systematic analysis of 5 methodologically similar studies for: 1. Character of the ethical conflict. 2. Similarities & differences in how conflicts were experienced & resolved. 3. Themes within the speciality areas.	The ethical conflicts were experienced as moral distress, moral uncertainty and moral dilemmas- these are defined according to Jameton. A significant number of ethical conflicts were experienced as moral distress. Resolution was variable, depending on the speciality area of practice. Moral uncertainty was the least experienced.
Reed & Rishel	To suggest that epistemic injustice may be an important contributing factor to nurse	Conceptual argument, hypothetical case study and empirical literature to support.	Focusing on frontline clinical RNs, the authors agree patients are being nursed longer in ICUs rather than receiving palliative care which places nurses in

(2015), USA, theoretical	moral distress & that hospital policy may be one approach to address this problem.		ethically challenging situations. RNs carry considerable moral burden as the most trusted profession. They are in close proximity to the patient yet may not be informed about all of the treatment decisions whilst expected to advocate, especially in end-of-life scenarios- moral distress is inevitable. This places the nurses in a position of epistemic injustice. Epistemic injustice is of 2 kinds: 'testimonial injustice' & 'hermeneutical injustice'.
Rushton et al. (2015), USA, quantitative	To assess nurse characteristics for burnout, moral distress & resilience across 6 'high-stress' units. RNs ($n=114$) from 4 hospitals in one health system, pooled from 6 'high-stress' units: 2 paediatric/neonatology, 2 oncology and 2 adult critical care units.	Cross-sectional survey, 6 survey tools (Maslach Burnout Inventory, Moral Distress Scale (Corley's), Perceived Stress Scale, Resilience Scale, Meaning Scale, State Hope Scale) and socio-demographic data. All completed online, taking up to 30 minutes per participant.	Moral distress defined as occurring when "the person is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgement about the correct action; yet as a result of real or perceived constraints participates in perceived moral wrongdoing"(Nathaniel, 2002). Similarity across clinical groups on all 6 survey tools, with the exception of higher levels of self-reported moral distress in adult critical care staff (mean SD= 69.1) than in neonate/paed (49.4) & med/surg/oncology (41.8) $p=0.002$.
Thomas & McCullough (2015), USA, theoretical	To classify the philosophical concepts within moral distress into distinct categories- to provide philosophical clarity and guide further empirical & philosophical investigations.	Conceptual analysis, beginning with Jameton's definition, utilizing literature that extends Jameton's definition & that "point toward a philosophical taxonomy of ethically significant moral distress" (p.105).	Jameton's definition consists of 2 key components: 1. Moral knowledge about what one ought to do in specific circumstances. 2. Organisational constraints on implementing that knowledge. They elaborate on 2- arguing that 'institutional constraints' take the form of challenges to, threats to, & violations of professional & individual integrity. These 6 stages are said to provide further evidence of the crescendo effect & moral residue.
Webster & Baylis (2000), USA, theoretical	To discuss the healthcare ethics consultant's experience of moral distress that can lead to compromised moral integrity and moral residue.	Theoretical.	Moral distress defined according to Jameton (1984). Argue his definition is too 'narrow'- distinguishes moral uncertainty from moral distress, stating that moral distress occurs "when there is incoherence between one's beliefs and one's action, and possibly also outcomes."(p.218) moral distress can also occur when one fails to pursue what one believes to be the right course of action, for example due to an error of judgment, personal failing. Introduce the concept of 'moral residue'- when in the face of moral distress we have "seriously compromised ourselves or allowed ourselves to be compromised- due to error (realisation of error) or a cause of error (incremental loss of

			commitment to previously held values for reasons of self-interest, i.e. self-protection, self-promotion).”
Whitehead et al. (2014), USA, quantitative	To assess and compare levels of moral distress amongst healthcare professionals, relationships between moral distress, perception of ethical climate, intent to leave, education in end of life care (EOL) & pain management. Total healthcare professionals ($n=592$); RNs ($n=395$); Physicians ($n=111$); others healthcare professionals ($n=86$) of which ($n=45$) provide direct patient care (physical therapists, respiratory therapists, occupational therapist, speech therapist) and ($n=41$) provide indirect patient care (chaplains, dieticians, pharmacists, social workers) from 1 healthcare system. RR 22%.	MDS-R from Hamric et al. (2012), items reworded for different professions, 0-4 scale, measuring frequency & intensity. Shortened Olson’s HECS-S from Hamric & Blackhall (2007). Surveys distributed via a web-based system to all healthcare professionals. Cronbach α 0.90.	Higher moral distress scores for RNs (M 82.9) & other healthcare professionals’s involved in direct care (84.1) compared to Drs (65.8) & healthcare professionals in indirect care (47.6). Higher moral distress in ICU setting (89.0) compared to non-ICU (70.5) ($p=0.008$). Variability of moral distress scores within professions. HEC-S scores negatively correlated with MDS-R mean scores ($p<0.0001$) - higher perceptions of ethical climate were associated with lower moral distress scores. Physicians had more positive perception of HEC. Participants had considered leaving/ left a previous position had higher moral distress scores. 20% RNs, 18% Drs, 12% healthcare professionals considering leaving.
Wiegand & Funk (2012), USA, mixed-methods	To identify clinical situations that cause moral distress, the consequences of those experiences & whether nurses change their practice based on the experience of moral distress. Critical care nurses ($n=47$, <i>although authors state 49 in the abstract</i>) from one university hospital. Convenience sample of RNs from 6 adult critical care	Open-ended surveys. Exact wording of the survey questions are not provided. The authors asked for a description of a situation that contributed to an experience of moral distress, how they addressed the situation, effects on the patient, family and healthcare providers & what they might do if faced with a similar situation in the future. Qualitative Data	Moral distress defined as “a type of moral conflict that occurs when one knows the right thing to do, but can’t pursue the right action.”- defined at the top of the survey. 79% experienced moral distress, 21% had not. Situations causing moral distress: 73% end of life; 59% medical futility; 11% organ donation; 8% under or overuse of analgesics. One direct example of a participant’s experience of moral distress provided. Negative consequences for patients and family members were described. Personal & professional consequences of moral distress for RNs listed.

	units. First question asked if respondents experienced moral distress, if yes they continued, 10 had not experienced moral distress, 37 had & so completed the entire survey.	Analysis Software (ATLAS.ti) used to manage data & code themes. Data analysed inductively. 10 random surveys analysed by co-author to check consistency. RR= 23%.	
Wilkinson (1987/88), USA, qualitative	To explore moral distress as experienced by nurse in acute care, to generate theory about the relationship between moral aspects of nursing & the quality of patient care. List of nurse's supplied by the State Board of Nursing- a random sample of 3790 nurse's were selected & letters of invitation sent out. 26 responses received, but only 24 interviewed- no explanation provided. It emerged that 11 of the RNs were no longer staff nurses, but they decided to interview for comparative data.	Face-to-face interviews (<i>n=24</i>), 13 staff nurses from acute care setting, 11 non-staff nurses with experience in acute care. Audio recorded & transcribed. Open-ended questions with prompts. Examples from participants presented verbatim. Few indications of reflexivity but did reflect on their impression of the participants. As 'indicators' emerged they developed 3 models- a 'moral distress equation', 'moral outrage equation' & 'moral distress model' to show the relationship between the indicators- potentially simplistic, linear & reductionist.	Moral distress defined as "the psychological disequilibrium & negative feeling state experienced when a person makes a moral decision but does not follow through by performing the moral behavior indicated by that decision" (p.16). 7 indicators identified that either contribute to, or are influenced by moral distress: 1. Kinds of cases- often related to prolonging life. 2 .Frequency of occurrence. 3 .Contextual constraints. 4. Feelings. 5. Effect of moral distress on nurses' wholeness. 6. Effect of moral distress on patient care. 7. Coping behaviours.

Appendix 8: Interview Guide

The questions and probes below are illustrative only and do not represent a script. Whilst they indicate the scope and tone of topics that may be raised, the conduct or content of the interview cannot be scripted in advance.

The overarching method for these interviews is 'Feminist Interpretive Phenomenology' and consistent with this, questions are left as open as possible so that the participant can select which experiences they want to discuss.

Introduction:

- Introduce self and project.
- Assure confidentiality: unless any cause for concern about yours or anyone else's safety – then a senior colleague may be notified.
- Confirm consent, consent to interview, consent form initialed and signed with a copy to keep.
- Remind participant of 4-week window to withdraw and refer to designated number for withdrawal.
- No right or wrong answers.

Start with some information about clinical background:

- Age
- Clinical area/speciality
- Years in current role
- Years registered as a nurse
- Education

Interview:

Suggested broad beginning questions:

1. What sort of work-related issues are likely to preoccupy you after your shift has finished?
2. What, if anything, that is work-related, keeps you awake at night?
3. What kind of issues do you find challenging or distressing at work?
4. Does anything bother you about work?
5. Are there any clinical scenarios or encounters that you find challenging?
6. Can you describe the sorts of ethical issues/problems that you encounter at work?
7. Can you think of a time where you felt compromised as a nurse?
8. What do you think moral distress is?
9. Do you find moral distress to be a negative or a positive experience?

Suggested probes:

1. Can you provide a background of the patient, such as why they were in hospital?
2. Can you describe more about the experience?
3. Can you describe the ethical issues?
4. Can you describe how the experience made you feel?
5. Can you describe how the experience made you feel afterwards?

6. Can you describe any thoughts/feelings you might have had after the experience?
7. Do you think this experience impacted your practice in anyway?
8. How do you think you would respond in the future to a similar situation?
9. Can you provide an example?

Suggested follow-up questions:

1. Did you seek any support during, or after this experience?
 - a) If so, what kind – formal/informal?
 - b) Did you find that support helpful?
2. Did you receive any support during or after this experience?
 - a) If so, what kind – formal/informal?
 - b) Did you find that support helpful?
3. Did you find anything you did yourself to be helpful?
4. What support would you find helpful in the future should a similar situation occur?
5. Did you reflect upon the experience afterwards?
6. Did you discuss the experience with anyone?
7. Did you discuss the experience with your colleagues?
8. How did you find the response of your colleagues during/after your experience?
9. Has your experience affected the way you respond to your colleagues?

Generic probes:

- Can you tell me a bit more about that?
- And then what happened?
- How did you feel about that?
- What was the most difficult/positive aspect?
- What was helpful?
- What worked well?
- What help would you have liked?

Closing the interview:

I want to thank-you for your time today. It is greatly appreciated.

Do you have any questions for me?

Appendix 9: Email to Unit Managers

REC Reference Number:

Dear _____

I am a Registered Nurse and I am carrying out a study to explore the ethical issues and moral problems that arise whilst nurses carry out their clinical duties at work. Research in the United States has shown that nurses deal with ethical problems on a daily basis but often do not feel that their moral viewpoint is heard and this can result in feelings of 'moral distress', although moral distress can occur for multiple reasons.

Within this study, we would like to learn whether this is something that nurses working in critical care areas in the United Kingdom also experience. I am aiming to recruit nurses working in critical care and the only inclusion criteria is that they currently work in critical care and that they are registered with the NMC. This research project will contribute to my PhD at The University of Bristol and has been sponsored by The Wellcome Trust.

Complex ethical issues often arise in critical care environments and therefore we are aiming to recruit from Intensive Care Units/ High Dependency Units such as yours. It is hoped that the information we gather will help us to understand the types of moral problems that arise in the clinical environment and the ways in which nurses can be supported in the future. All participant and Hospital trust information will remain confidential, and all data will be anonymised.

I would be very grateful if you would be willing to circulate the attached Participant Information Letter amongst the nurses working on your unit then I would greatly appreciate it. In two weeks I will then ask you to recirculate these emails amongst all of the nurses you originally emailed.

If you require any further information then please do not hesitate to contact me.

Yours sincerely,

Georgina Morley
07766952317
gm17072@bristol.ac.uk

Appendix 10: Information Sheet for Potential Participants (site 1)



Information Sheet for Potential Participants

What is 'moral distress' in nursing and how should we respond to it?

IRAS ID number: **197577** REC Reference Number: **ERN_15-1168S**

You are invited to participate in this research study because you are a nurse registered with the Nursing and Midwifery Council (NMC) and you are currently working in an Intensive Care Unit (ICU) or High Dependency Unit (HDU) at your hospital Trust.

Before you decide whether you want to take part in this study it is important for you to understand why the research is being done and what your participation will involve. Please take the time to read the following information carefully. Please do ask if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of this study is to explore the ethical issues and moral problems that you face when carrying out your clinical duties at work, and how experiencing these problems makes you feel. Research in the United States has shown that nurses deal with ethical problems on a daily basis but often do not feel that their moral viewpoint is heard and this can result in feelings of 'moral distress'. Moral distress can occur for multiple reasons. Within this study, we would like to learn whether this is something that nurses working in critical care areas in the United Kingdom also experience and how these experiences make you feel. It is hoped that this information can help us to understand the types of moral problems that arise in the clinical environment and ways in which nurses can be supported in the future.

If you are unsure about whether or not you think you have experienced ethical issues at work, but you are still interested, then please still get in touch.

How will the study be conducted and by whom?

A Registered Nurse and PhD student, Georgina Morley is conducting this qualitative study as part of a PhD in Biomedical Ethics at The University of Bristol, which is funded by The Wellcome Trust.

If you agree to take part you will be invited to an interview in a quiet room in a mutually convenient quiet location. The interview will be arranged at your convenience and should last between 30-60 minutes. During this time you will be asked about the times you have experience ethical issues at work and how this made you feel.

Do I have to agree?

Taking part is voluntary, and it is up to you whether you decide to participate. You may withdraw up until 4 weeks after your interview and without giving a reason. After this time, however, your data will have already been analysed and therefore cannot be withdrawn. Although I can reassure you that if you do wish to withdraw after the 4 weeks is up, then your contribution will not be quoted in any publication

or write up. Once the study is published it will not be possible to withdraw at all. We anticipate publication in late 2018.

Will what I say be kept confidential?

All personal information that you provide will be kept confidential, and all research data will be anonymised. At the start of the study you will be assigned a random number and this will remain as your identifier throughout. This way nobody will be able to associate the information that you give with you or your organisation. The interview will be recorded on an audio device and transcribed by an external company who will not have access to your identity and who guarantee confidentiality and security of data. The research material will be stored securely, will only be available to the research team and will be destroyed after ten years. Your personal data, such as email address and contact number will be stored securely on an encrypted USB stick, which will be used solely for that purpose and stored securely. Your personal data will be retained until the end of the project, or if you have requested a copy of the published report, your email address will be retained up until that time.

The research results will be written up as part of the PhD thesis and the anonymised results included in a peer-review journal. Anonymous quotes will be used but you will not be identified personally. You will be asked to consent for your anonymised data to be used for these purposes. If you wish to be informed upon publication, then this can be arranged with the research team.

What are the benefits and risks?

The aim of the project is to understand the ethical issues nurses experience when carrying out their clinical duties, and to understand what support they may require. Due to your busy work environment, you may not be able to carry out the interview during your contracted work hours. In this case, we can find a time and location that suits you best. You will be offered a £20 Amazon voucher as reimbursement of travel expenses. There are no other direct benefits to taking part, although, some people may find discussing their clinical experiences beneficial and participants are entitled to a copy of the results.

However, it is possible that you might find talking about some ethical issues distressing. In this event you are advised to contact your Trust staff support service where a confidential counsellor is available. This is provided through your Occupational Health service where you can talk to a trained counselor free. [CONTACT DETAILS FOR OCCUPATIONAL HEALTH SERVICE- DELETED FOR CONFIDENTIALITY]

Additionally, in the unlikely event that you say anything that causes concern about yours or anyone else's safety then, in accordance with the Nursing and Midwifery Council's code of conduct, I would be obliged to inform a senior colleague. In this unlikely event, the research team would be consulted and I will advise you of my need to inform current employers and the NMC.

Who can I contact for further information?

If you would like to discuss any aspects of this study or would like to participate, please contact the researcher: gm17072@bristol.ac.uk

If after participating, this study has harmed you in any way or you have any concerns about your contribution or conduct of this study, you may contact the project supervisory team.

Dr Jonathan Ives: j.ives@bristol.ac.uk
Dr Caroline Bradbury-Jones: c.bradbury-jones@bham.ac.uk
Professor Fiona Irvine: F.E.Irvine@bham.ac.uk

Thank you for considering participation in this project.



Appendix 11: Information Sheet for Potential Participants (site 2)



Information Sheet for Potential Participants

What is 'moral distress' in nursing and how should we respond to it?

IRAS ID number: **197577** REC Reference Number: **ERN_15-1168S**

You are invited to participate in this research study because you are a nurse registered with the Nursing and Midwifery Council (NMC), you are currently working in an Intensive Care Unit (ICU) or High Dependency Unit (HDU), where you have worked for at least 6 months, at [YOUR HOSPITAL TRUST- DELETED FOR CONFIDENTIALITY]

Before you decide whether you want to take part in this study it is important for you to understand why the research is being done and what your participation will involve. Please take the time to read the following information carefully. Please do ask if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of this study is to explore the ethical issues and moral problems that you face when carrying out your clinical duties at work, and how experiencing these problems makes you feel. Research in the United States has shown that nurses deal with ethical problems on a daily basis but often do not feel that their moral viewpoint is heard and this can result in feelings of 'moral distress'. Moral distress can occur for multiple reasons. Within this study, we would like to learn whether this is something that nurses working in critical care areas in the United Kingdom also experience and how these experiences make you feel. It is hoped that this information can help us to understand the types of moral problems that arise in the clinical environment and ways in which nurses can be supported in the future.

If you are unsure about whether or not you think you have experienced ethical issues at work, but you are still interested, then please still get in touch.

How will the study be conducted and by whom?

A Registered Nurse and PhD student, Georgina Morley is conducting this qualitative study as part of a PhD in Biomedical Ethics at The University of Bristol, which is funded by The Wellcome Trust. The project has been approved by the University of Birmingham Science, Technology, Engineering and Mathematics Ethical Review Committee [CONTACT DETAILS DELETED FOR CONFIDENTIALITY]

If you agree to take part you will be invited to an interview in a quiet room in a mutually convenient quiet location. The interview will be arranged at your convenience and should last between 30-60 minutes. During this time you will be asked about the times you have experience ethical issues at work and how this made you feel.

Do I have to agree?

Taking part is voluntary, and it is up to you whether you decide to participate. You may withdraw up until 4 weeks after your interview and without giving a reason.

After this time, however, your data will have already been analysed and therefore cannot be withdrawn. Although I can reassure you that if you do wish to withdraw after the 4 weeks is up, then your contribution will not be quoted in any publication or write up. Once the study is published it will not be possible to withdraw at all. We anticipate publication in late 2018.

Will what I say be kept confidential?

All personal information that you provide will be kept confidential, and all research data will be anonymised. At the start of the study you will be assigned a random number and this will remain as your identifier throughout. This way nobody will be able to associate the information that you give with you or your organisation. The interview will be recorded on an audio device and transcribed by an external company who will not have access to your identity and who guarantee confidentiality and security of data. The research material will be stored securely, will only be available to the research team and will be destroyed after ten years. Your personal data, such as email address and contact number will be stored securely on an encrypted USB stick, which will be used solely for that purpose and stored securely. Your personal data will be retained until the end of the project, or if you have requested a copy of the published report, your email address will be retained up until that time.

The research results will be written up as part of the PhD thesis and the anonymised results included in a peer-review journal. Anonymous quotes will be used but you will not be identified personally. You will be asked to consent for your anonymised data to be used for these purposes. If you wish to be informed upon publication, then this can be arranged with the research team.

What are the benefits and risks?

The aim of the project is to understand the ethical issues nurses experience when carrying out their clinical duties, and to understand what support they may require. Due to your busy work environment, you may not be able to carry out the interview during your contracted work hours. In this case, we can find a time and location that suits you best. You will be offered a £20 Amazon voucher as reimbursement of travel expenses. There are no other direct benefits to taking part, although, some people may find discussing their clinical experiences beneficial and participants are entitled to a copy of the results.

However, it is possible that you might find talking about some ethical issues distressing. In this event you are advised to contact [CONTACT DETAILS FOR DELETED FOR CONFIDENTIALITY]

Additionally, in the unlikely event that you say anything that causes concern about yours or anyone else's safety then, in accordance with the Nursing and Midwifery Council's code of conduct, I would be obliged to inform a senior colleague [CONTACT DETAILS FOR OCCUPATIONAL HEALTH SERVICE- DELETED FOR CONFIDENTIALITY] who would look at the issues raised and decide upon further action. In this unlikely event, the research team would be consulted and I will advise you of my need to inform current employers and the NMC.

Who can I contact for further information?

If you would like to discuss any aspects of this study or would like to participate, please contact the researcher: gm17072@bristol.ac.uk

If after participating, this study has harmed you in any way or you have any concerns about your contribution or conduct of this study, you may contact [CONTACT DETAILS DELETED FOR CONFIDENTIALITY] or the project supervisory team. [CONTACT DETAILS DELETED FOR CONFIDENTIALITY]

Dr Jonathan Ives: j.ives@bristol.ac.uk

Dr Caroline Bradbury-Jones: c.bradbury-jones@bham.ac.uk

Professor Fiona Irvine: F.E.Irvine@bham.ac.uk

Thank you for considering participation in this project.



Appendix 12: Lone Worker Considerations

The Principal Investigator (GM) gave participants the option to be interviewed at their home. In order to help ensure her safety, a number of considerations were made and specific procedures put in place. These are adapted from the Code of Practice for the Safety of Social Researchers from the Social Research Association, and recommended by The University of Birmingham for working off campus.

- Considerations of competence- GM has previously conducted a community nursing placement which consisted of a period of time working alone and has previous experience of lone working. GM has also had previous de-escalation training.
- Risks to personal safety- recruitment posters and recruitment information was circulated in staffing areas of recruitment sites, and not publicly and so risks to personal safety were judged to be low.
- Assessing risks in the fieldwork site- each home was assessed on the basis of the safety of the local community and ease of access to local public transport, and if the risk was believed to be high, the interview was arranged for a different location such as the participants place of work.
- Interview precautions- GM ensured that she planned the route prior to the interview, carried her university ID card, mobile telephone and coins for use in a telephone box.
- Maintaining contact- the address, contact number, name of the participant, time of interview and anticipated finish time were all forwarded to the project supervisors the day before the interview with a time scheduled for GM to contact them. If the supervisory team did not hear from GM then they would contact her and escalate if necessary.
- Strategies for risky situations- a trigger phrase was agreed amongst the research team to indicate that GM required help.
- Evaluation- it was agreed that if an incident did occur then it would be discussed amongst the team, discussed and reflected upon in order to be incorporated into future risk assessments.

Appendix 13: Ethical Approval Documents

Miss Georgina Morley
113 Red Square, 3 Piano Lane
Carysfort Road
Stoke Newington, London
N16 9AY

Email: hra.approval@nhs.net

30 June 2016

Dear Miss Morley

Letter of HRA Approval

Study title:	What is 'moral distress' in nursing and how should we respond to it?
IRAS project ID:	197577
REC reference:	16/HRA/1753
Sponsor	University of Birmingham

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

IRAS project ID	197577
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HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

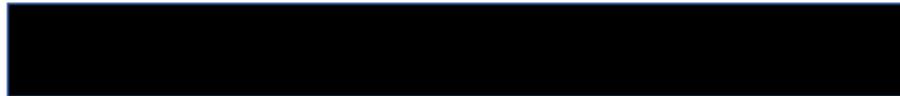
Your IRAS project ID is **197577**. Please quote this on all correspondence.

Yours sincerely

Thomas Fairman
HRA Assessor

Email: hra.approval@nhs.net

Copy to: *Dr Sean Jennings, University of Birmingham, (Sponsor Contact)*



NIHR CRN Portfolio Applications Team

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. NIQB) and all correspondence [Confirmation of ethical approval]		
Confirmation of any other Regulatory Approvals (e.g. NIQB) and all correspondence [Sponsorship certificate]		15 June 2016
Copies of advertisement materials for research participants [Recruitment poster, ██████████]	v1.1	13 May 2016
Copies of advertisement materials for research participants [Recruitment poster, ██████████]	v1.1	13 May 2016
Copies of advertisement materials for research participants [Recruitment advert for intranet]	v1.0	17 November 2015
Covering letter on headed paper [Covering Letter]		02 June 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Confirmation of insurance]	v1.0	31 May 2016
Interview schedules or topic guides for participants [Topic Guide]	v1.0	13 May 2016
IRAS Application Form [IRAS_Form_02062016]		02 June 2016
Letter from funder [Award letter, confirmation of funding]		02 June 2016
Letter from sponsor [Confirmation of sponsorship]		02 June 2016
Letters of invitation to participant [Recruitment letter, ██████████]	v1.1	13 May 2016
Letters of invitation to participant [Recruitment email, ██████████]	v1.0	17 November 2015
Other [HRA Schedule of Events]	2.0	15 June 2016
Other [HRA Statement of Activities]	2.0	15 June 2016
Participant consent form [Consent form, ██████████]	v1.4	13 June 2016
Participant consent form [Consent form, ██████████]	v1.3	13 June 2016
Participant information sheet (PIS) [Information Sheet, ██████████]	1.4	13 June 2016
Participant information sheet (PIS) [Information Sheet, ██████████]	v1.3	13 June 2016
Research protocol or project proposal [Research Protocol]	v1.3	13 June 2016
Summary CV for Chief Investigator (CI) [CI CV 2016]		06 March 2016
Summary CV for supervisor (student research) [Short CV-JI]	v1.0	05 May 2016
Summary CV for supervisor (student research) [Short CV-FI]	v1.0	05 May 2016
Summary CV for supervisor (student research) [Short CV-HD]	v1.0	05 May 2016

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Dr Sean Jennings, University of Birmingham, (researchgovernance@contacts.bham.ac.uk, 01214158011)

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor has submitted a Statement of Activities and indicated that they intend for this to form the agreement between the sponsor and participating sites. The sponsor is not requesting, and does not require any additional agreements.

IRAS project ID	197577
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Section	HRA Assessment Criteria	Compliant with Standards	Comments
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	The study is funded by The Wellcome Trust. No study funding will be provided to study sites, as detailed in Schedule 1 of the Statement of Activities.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Not Applicable	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

All participating organisation will undertake the same study activities, as detailed in the IRAS

application and supporting study documents. There is therefore only one site type participating in the research.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England that are participating in the study **will be expected to formally confirm their capacity and capability** to host this research.

- The sponsor should ensure that participating NHS organisations are provided with a copy of this letter and all relevant study documentation, and work jointly with NHS organisations to arrange capacity and capability whilst the HRA assessment is ongoing.
- Further detail on how capacity and capability will be confirmed by participating NHS organisations, following issue of the Letter of HRA Approval, is provided in the *Participating NHS Organisations and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections of this appendix.

The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

Local Collaborators should be appointed at study sites. The sponsor has confirmed that no assistance is required from study sites identifying suitable individuals to fulfil this role at site.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

IRAS project ID	197577
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This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Should any study activities be undertaken by individuals who do not hold an appropriate pre-existing contractual relationship with the relevant organisation a Letter of Access should be sought. The following pre-engagement checks would be required:

- Criminal Record Check
- Occupational Health Clearance

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.

Miss Georgina Morley
PhD Student, Ethics in Medicine
School of Social and Community Medicine
Carynge Hall
39 Whatley Road
Bristol
BS8 2PS

6th April 2017

Dear Georgina

AGREEMENT BY THE UNIVERSITY OF BRISTOL TO ACT AS RESEARCH SPONSOR.

Project Title: What is 'moral distress' in nursing and how should we respond to it?
(our ref 2774)

Chief Investigator: Miss Georgina Morley, PhD student

Study duration	1.7.16 – 2.10.17
Ethics	University of Birmingham Science, Technology, Engineering and Mathematics Ethical Review Committee, 1.3.16, ERN_15-1168S
IRAS ID	197577
HRA Approval	Versions of study documents as detailed on HRA approval (dated 30.6.17) HRA Approval of Amendment 1 transferring Sponsorship to the University of Bristol, 5.4.17
Insurance reference	CT2140
Funder	Wellcome Trust Fellowship
NHS Approval	
Confirmation of Capacity and Capability from participating NHS organisation	

The University of Bristol hereby confirms that it agrees to act as the research sponsor for the above referenced project with you as Chief Investigator in the locations detailed in the table above. This study was originally Sponsored by the University of Birmingham (Sponsor confirmation dated 27.5.16, Ref RG_15-182); Sponsorship has been taken on by the University of Bristol following the transfer of your PhD to this University.

We would like to remind you of your obligation to comply with all relevant regulatory guidance and legislation.

If you intend to make any changes to the study, including an extension to the end date, you must inform us as Sponsor prior to submission to the Regulatory Authority. Annual Progress Reports are due on the anniversary of when HRA Approval and/or NHS REC favourable opinion was granted, please send us a copy.

The University currently monitors approximately 10% of active studies via a Service Level Agreement with UH Bristol. If your study is selected for monitoring you will be contacted by members of UH Bristol.

May we take this opportunity to wish you every success with your research.

Yours sincerely

A handwritten signature in black ink, appearing to read 'BWK', written in a cursive style.

Birgit Whitman
Head of Research Governance

cc: Dr Jonathan Ives, SSCM



UNIVERSITY OF
BIRMINGHAM

Finance Office

Professor Fiona Irvine
School of Health and Population Sciences
University of Birmingham

27th May 2016

Dear Professor Irvine

Project Title: What is 'moral distress' in nursing and how should we respond to it?
Sponsor Reference: RG_15-182
ERN reference: ERN_15-1168

Under the requirements of Department of Health Research Governance Framework for Health and Community Care, the University of Birmingham agrees to act as Sponsor for this project. Sponsorship is subject to you obtaining a favourable ethical opinion and NHS R&D management approval where appropriate.

As Chief Investigator, you must ensure that local study recruitment does not commence until all applicable approvals have been obtained. Where a study is or becomes multi-site you are responsible for ensuring that recruitment at external sites does not commence until local approvals have been obtained.

Following receipt of all relevant approvals, you should ensure that any subsequent amendments are notified to the Sponsor, REC and relevant NHS R&D Office(s), and that an annual progress report is submitted to the Sponsor, REC and NHS R&D departments where requested.

Please ensure you are familiar with the University of Birmingham Code of Practice for Research (<http://www.birmingham.ac.uk/Documents/university/legal/research.pdf>) and any appropriate College or School guidelines.

Finally please contact researchgovernance@contacts.bham.ac.uk should you have any queries.

You may show this letter to external organisations.

Yours sincerely

Dr Sean Jennings
Head of Research Governance and Ethics
Research Support Group

University of Birmingham, Edgbaston, Birmingham, B15 2TT, United Kingdom
w: www.finance.bham.ac.uk



Appendix 14: Consent Form (site 1)



CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of the Research Project: **What is ‘moral distress’ in nursing and how should we respond to it?**

IRAS ID number: **197577**

REC Reference Number: **ERN_15-1168S**

Principle Investigator: Georgina Morley

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. One copy of this Consent Form will be retained by the researcher and another for the participant to keep and refer to at any time.

Please initial box

- I confirm that I have read and understood the participant information sheet (v1.4 6th March 2017) for the above study. I have had the opportunity to consider this information, ask questions, and those questions have been answered to my satisfaction.
- I understand that participation is voluntary, and that I am free to withdraw, without giving a reason up until 4 weeks after the interview and that withdrawal will not affect me in any way. If I withdraw after 4 weeks, I understand that my data will have been used and so will not be withdrawn, but I will not be anonymously quoted. I understand that I cannot withdraw at all once the study has been published.
- I understand that I will be asked to participate in a one-to-one interview with the Principal Investigator and that this interview will be audio recorded.
- I understand that neither I, nor my Trust will be identified in the study, or in any subsequent publication and use. My name and my Trust's name will be removed and my comments made unattributable.

- I consent to this interview being audio recorded and verbatim transcribed, and for use of anonymised direct quotations to be included in the PhD thesis and any future publications.

- I am aware that the transcribed data will be entered into a filing system or database, will only be accessed by authorised personnel involved in the project. The information will be retained by the University of Bristol and will only be used for the purpose of research, and statistical and audit purposes.

- I understand that my personal data will be processed for the purposes detailed above, in accordance with the Data Protection Act 1998.

- I understand that in recognition of my time contribution, that I will receive one £20 Amazon voucher.

- I agree to participate in this study.

Name of participant..... Date.....
 Signature.....

Name of researcher/
 individual obtaining consent..... Date.....

Appendix 15: Consent Form (site 2)



CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of the Research Project: **What is 'moral distress' in nursing and how should we respond to it?**

IRAS ID number: **197577**

REC Reference Number: **ERN_15-1168S**

Principle Investigator: Georgina Morley

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. One copy of this Consent Form will be retained by the researcher and another for the participant to keep and refer to at any time.

Please initial box

- I confirm that I have read and understood the participant information sheet (v1.5 6th March 2017) for the above study. I have had the opportunity to consider this information, ask questions, and those questions have been answered to my satisfaction.
- I understand that participation is voluntary, and that I am free to withdraw, without giving a reason up until 4 weeks after the interview and that withdrawal will not affect me in any way. If I withdraw after 4 weeks, I understand that my data will have been used and so will not be withdrawn, but I will not be anonymously quoted. I understand that I cannot withdraw at all once the study has been published.
- I understand that I will be asked to participate in a one-to-one interview with the Principal Investigator and that this interview will be audio recorded.
- I understand that neither I, nor my Trust will be identified in the study, or in any subsequent publication and use. My name and my Trust's name will be removed and my comments made unattributable.
- I consent to this interview being audio recorded and verbatim transcribed, and for use of anonymised direct quotations to be included in the PhD thesis and any future publications.

- I am aware that the transcribed data will be entered into a filing system or database, will only be accessed by authorised personnel involved in the project. The information will be retained by the University of Bristol and will only be used for the purpose of research, and statistical and audit purposes.

- I understand that my personal data will be processed for the purposes detailed above, in accordance with the Data Protection Act 1998.

- I understand that in recognition of my time contribution, that I will receive one £20 Amazon voucher.

- I agree to participate in this study.

Name of participant..... Date.....
 Signature.....

Name of researcher/
 individual obtaining consent..... Date.....
 Signature.....

Appendix 16: Excerpt from Reflexive Research Diary

Van Manen (1990) discusses how autobiographies, diaries and journals are experiential sources. This reflexive research diary will record some of my developing thoughts about moral distress and will provide a place for me to write my reflections following the interviews. I will first discuss how I came to be interested in moral distress and the assumptions that I had before I began this project. The diary will then move on to being a more practical tool to aid my data analysis. I will note down my reflections from the initial interviews and document the significant stages of data analysis and the development of themes.

My Background

I completed my MSc in 2014 and explored nurses' experiences of patients with substance-use disorder (SUD) in pain. This initial project was inspired by my own experiences during my first clinical job on a trauma unit. I found that these patients with SUD were difficult to manage and often their pain was a huge issue. I noticed that healthcare professionals seemed to use specific terms to describe these patients and when I explored the literature I found that stigmatising and stereotyping of patients with SUD was a common finding but that there was limited literature exploring how to manage their pain.

After interviewing five nurses, one theme that came out of the data was, "doing the 'right thing'", which related to both patients and staff. I found that nurses' own moral judgements and their moral judgements of patients affected their pain management strategies. For example, patients on a methadone programme were seen more favourably because they were viewed as trying to do the 'right thing' and nurses' discussed conflicts with physicians regarding the 'right thing'. One participant felt torn because they didn't want the patient to be in pain but equally didn't want to feed their addiction. Although this theme came out of the data, I didn't have enough space in which to thoroughly explore it but it made me think about all the times that both myself and the nurses I worked with had struggled to do the right thing. Upon reflection, these initial thoughts and feelings are compatible with Jameton's original conception of moral distress.

Despite having completed a Philosophy degree prior to my nursing qualification, I had up until this point been very much concentrating on my clinical skills and had overlooked the ethical aspects of care. My MSc really focused my attention on bioethics. Upon reflection, I am shocked by how little ethics and law teaching and preparation we had. Nonetheless, my MSc work highlighted how nurses are constantly striving to 'do the right thing' and how nursing is inherently an ethical endeavour. I stumbled across the term moral distress and was fascinated. I felt that in many ways it captured the experiences I had.

Reflections Post Interview

Key words: KILLING AND LETTING DIE, 'JUST' A NURSE

This participant was extremely articulate and self-aware. She had clearly given a lot of thought to her ethical beliefs, whether this was rooted in the experience she went on to describe or because she just was a very reflective person, was not clear. I think we both immediately felt at ease in each other's company because we were a similar age. I could imagine us being friends. But I had to- and I think I did - manage to put this aside for the interview, maintain the same sort of relationship that I have managed with patients who I had a rapport with and could imagine being friends with.

At the end of the interview I shared a similar feeling with the participant as she described withdrawing life-sustaining treatment from a patient. I had taken a hypoxic patient off a ventilator for the first time and was shocked by how I had felt afterwards. Similarly to the participant, it felt very palpably like I had killed someone. I believe in the notion of a 'good' death and I suppose I believed I was doing the 'right thing'. Although I don't think I really had time to think about it - I had to look after that patient because that was where I had been assigned and the plan had been made in the day and the entire family were there and ready for this plan to be enacted.

The participant became really upset when talking about how everyday nursing actions have such huge implications. These experiences had clearly stayed with her and to some extent seemed to haunt her. Again, I could relate and I was surprised by the fact I could relate so closely to her experience. I think it's interesting that she describes this experience as a moral distress experience because she also seemed to feel very strongly that she did the right thing - but this seemed to conflict somehow with a deeper conviction that she caused that patient to die and that the act of withdrawing life-sustaining treatment is akin to murder.

Reflections post interview

Key words: CONSENT, PROXIMITY TO PATIENT, ROLE MORALITY- PROFESSIONAL VS. PERSONAL MORALS, ETHICS VS. LAW

This participant seemed very confident in her abilities and had been in ICU for a substantial amount of time. I got the distinct feeling that the experiences she shared were ones that she had very specifically wanted to talk about because they had troubled her for a couple of years. She seemed very prepared, not in a fabricated way but rather because she had gone over the events repeatedly in her own mind, questioning what the right thing had been. Again, she was very articulate, spoke freely and provided a lot of detail. I got the impression that she was very genuine and honest and didn't feel she had to censor her thoughts for the interview in any way. I think due to the fact we are both critical care nurses, this allowed us to build up a rapport easily through our shared experiences. She didn't have to explain complex terminology. I think this ease in explanation allowed her to speak freely and know we had some shared experiences and open up. She spoke about specifically going into her current role in order to take a break from clinical nursing and critical care.

General Reflections

I organised a conference in my first year and another student presented on moral distress. In his research, he discussed the value of moral distress and

argued that we should not aim to get rid of it completely. I don't think that many researchers have had the aim of getting rid of it completely but rather reduce it. Nonetheless, his ideas got me thinking about whether there is anything positive about moral distress so I asked this question in my interviews. The responses were very interesting as most participants said that although it is certainly a negative experience, it does highlight the fact that we care. Moral distress does seem to illuminate the moral issues. Anecdotally, I have heard lots of nurses say that they will quit when they stop caring and I wonder whether this shows the inevitability and necessity of moral distress; so long as you are a caring and compassionate nurse, you will feel morally distressed. Moral distress does seem to have some value but that doesn't mean we shouldn't work to reduce the negative psychological effects or find ways to support each other, it doesn't make it inherently valuable.

Reflections post interview

Key words: ETHICS IS ABOUT PREFERENCES, DECISION-MAKING, HIERARCHY, COMMUNICATION STRATEGIES, COMPASSION FATIGUE,

Reflecting on this interview I felt very puzzled. I wasn't convinced that she was being entirely honest with herself. She obviously volunteered to take part in this research but then in the interview focused on the fact she never did anything she didn't believe was the right thing. This seemed to be unlikely but I don't think the participant was trying to deceive me. I wondered if it was a defence mechanism- she couldn't bring herself to admit that she may have contributed towards someone else's suffering or whether she genuinely never carried out decisions she didn't believe were right. She discussed how conflicts and uncertainty about the right thing contributed to her feelings of distress.

Reflections during data analysis:

Analysing the data, I can understand why I felt confused about this interview. The participant seems to contradict herself a lot. She will say that nurses are part of the decision-making and are communicated with but then when probed she will say that actually often she has to ask the rationale and reasoning behind things- this paints a picture of a very pro-active nurse seeking to understand but who isn't readily included in decision-making and treatment decisions. She also discusses various communication strategies which shows that seem to suggest that she is a part of the hierarchy, rather than challenging it.

Appendix 17: Example of a Narrative

Freddie

Freddie seemed quite timid and shy. Freddie didn't really elaborate so I had to probe his responses to get fuller answers.

The first narrative he describes is of a case of perceived futile care and worries that false hope is being given to the family. He describes the difficulty of communicating honestly with the family when the Consultant is painting a more positive picture. He matter-of-factly described how the Consultant ignored his and his colleagues views (he emphasizes that even the senior nurses weren't listened to). It is interesting because there is no real sense of outrage about this. I wonder if nurses that feel more outraged also feel moral distress more keenly because of the sense of injustice? Freddie seems to indicate that he believed care was futile but when asked directly whether he thought he knew the right thing to do, he seems uncertain. He explains the belief that nurses should reduce suffering and help to facilitate a good death and futile care prevents this. Freddie describes how he likes to take off all of the monitoring equipment in ITU in order to help allow a 'good death'. He describes a good death as:

"...keeping, like your basic nursing care. Keeping your, keeping the patient comfortable, symptom, symptom control um, pain free, not loads of secretions. Just keeping them, like your basic nursing care, keeping them comfortable."

In the second narrative, the issue is still futile care but this time it is the family that want to continue aggressive treatments whilst the medical and nursing staff all agree that life-sustaining treatment should be withdrawn. Freddie felt that the first case was more distressing because the care they were providing was so much more aggressive than with the second patient. The first patient seemed dead already, he was peripherally and centrally shut down and felt cold and looked like he was dying. He felt he was causing more suffering to the first patient whereas the second had fixed, dilated pupils and seemed peaceful and unaware. Freddie thinks that the first case occurs more often than the second.

Freddie really struggled to find the right vocabulary and spends quite a lot of time trying to search for the right word or just repeating the same words. He seemed to lack ethical vocabulary and knowledge and so throughout the interview he hints at making decisions but never seems to explicitly lay out his beliefs and thoughts about what was wrong and right in each case. When asked whether he had received ethics education Freddie says he has had very little ethics education and that he thinks it would be very useful to help promote discussion- Freddie said it would not be good as an e-learning module!

Freddie discusses the belief that often nurses and doctors do have different perspectives because nurses tend to be more patient-centred whilst the doctors tend to see the disease. He describes having a different opinion to a doctor but

that once the doctor explained his opinion then he was able to get on board with this opinion. Freddie doesn't seem particularly outraged by the fact that doctors tend to just tell nurses what to do without explaining why.

As with the other participants (Chloe, Danielle, Grace) Freddie discusses how problematic it can be when the Consultants change over because they tend to change the treatment plans. This can be particularly difficult for the families because they then receive conflicting information. Many of the participants also discuss the difficulty of having visiting teams (Freddie, Grace) and how this can affect decision-making and presumably teamwork. This seems particularly to be an issue with trauma (Beth discusses this- all the visiting teams needing to review one patient) because there are so many specialities involved for all the affected parts of the body. Alternatively, as Danielle discusses- some teams that seem to get their patient admitted to ITU and demand very aggressive care that the ITU team don't necessarily agree with e.g., haem-oncology.

Unlike the other participants, it is less clear to what extent Freddie is distressed. He is very matter of fact and he doesn't really describe his emotions until I probe and ask specifically about how certain experiences made him feel. He seemed less open with his emotions and without wishing to stereotype, I did wonder whether that was because of his gender.

MORAL DISTRESS:

- Constrained moral judgement and moral uncertainty due to a lack of confidence, lack of ethics education.

"I think it's very, the way I think of it is it's very- it's difficult because we...like the consultants, I see the consultants as consultants for a reason and they understand a lot more about um, the sort of, like the physiology like behind it and they know a lot more about stuff like that so you, they're, it's very, like, I think we should have stopped sooner. And so like other, a lot of the doctor, like junior, more like registrars and stuff thought that as well. But it's very difficult to say that it's the wrong thing when they're the experts in it. Because it might not be the wrong thing, if you see what, like... So, and, like recently on this, recently there was a, I had a gentleman admitted who... the consultant wanted to withdraw on him and I thought oh he's getting, like he's getting better, I don't understand why. And then when he, like, explained a lot more about it you were like actually, like oh yeah, that's right kind of thing. So we do, I think it's very difficult to say what's right and what's wrong."

"I don't know if it's the right thing to do, like there's never any right or wrong thing to do I don't think."

"I feel that I decided, yeah, I think I decided the right thing to do for that patient at that time um, but then someone might say oh no, I don't think, and if you can say why then I'm perfectly happy to change my, like, say oh yeah, actually, yeah."

- Response to question, “what is moral distress?”

“It’s more, sort of, going against, not necessarily what you believe personally because, but more what you think you should be doing as a nurse and when you are having to make decisions, not make but when you’re having to do things that you feel is not the best thing to be doing for that patient, but that’s part of what has been decided is the plan kind of thing. Um, and yeah, that’s, kind of, just, when you don’t think it’s the right thing at all but you’re having to go against what you think, that’s what I kind of perceived it as.”

ISSUES DISCUSSED:

- Perceived futile care.
- Causing suffering.
- The nurses’ role is to advocate, not cause suffering and maintain dignity.

EFFECTS:

- Feeling devalued
- Upset
- Worry
- Problems sleeping

GM: *Ok, so how did that make you feel?*

“...it was a bit like you’re not really nursing because rather than, like you’re putting the patient through more distress really and the family through prolonging what is most like, like you never say never but what is most likely going to happen. Um, and sort of um, that, rather than trying to make it a bit nicer and more dignified it just, it went on and on for a very long time, when it probably didn’t really need to. And you just feel like you’re not doing what you’re supposed to do.”

- It is a nurses’ responsibility to reduce suffering and to allow a dignified death- Freddie was unable to do this because the Consultant wanted to continue aggressive treatments.

“...doing something that you feel very uncomfortable doing, prolonging, prolonging what is going to happen and causing more distress to yourself because you’re doing something that you don’t necessarily feel is the right thing to do and also distress to the family and the patient.”

COPING MECHANISMS:

- Informal debriefing with colleagues
- Formal debriefing- is offered but not always utilised. Important they aren’t connected to the unit so you can talk about people without fear of retribution.
- Would be good to have a counselling service- someone you could talk to about a particularly challenging patient/ shift- something away from the unit. BUT Freddie also says he would only use this service if he

couldn't speak to his nursing colleagues but that it could be helpful for others.

Key Words/ Key Themes:

(these are decided prior to identifying the most coded nodes)

DIGNITY

Most coded nodes:

1. Proximity to the patient
2. Family making healthcare decisions
3. Family in disagreement
4. Debriefing
5. Consultants (not family) make healthcare decisions
6. Futile Care
7. End of life care

Key quotations:

“So you can see, that, in a way that was kind of a moral thing as well because if you, if you could put yourselves in their position where they don't necessarily know a lot about what else is going on, like, the reasoning behind things, you can sort of see that, you could see why they're doing it but you know that they shouldn't be, you could sympathise with them but you know we shouldn't be filming in the unit, where you could get other patients and stuff like that in it. And that went on for quite, that went on for quite a long time. And that was when we had a proper um, debrief, like a sort of, we could talk to people and stuff about that.” (LACK OF ETHICS VOCABULARY)

GM: *What is the nurses' roles?*

“Sort of um, being, trying to advocate for the patient as far as you can do. Um, and so, also supporting the family trying to, because sometimes, I think families, they'll ask doctor something, like doctors will say something and then the family, even the doctor will be like oh do you understand? And they'll say yes and then they come out and they don't actually know what's been said. So trying to, because they did ask questions, so trying to answer their questions and sort of, and things like that and just work with the family rather than trying to work against them. Which is what we were trying to do.”

(NURSE AS ADVOCATE, NURSE AS TRANSLATOR, SUPPORT THE FAMILY)

“I think like trying to advocate for patients, stand up for them, which we tried to do in both situations. Supporting families, which we tried to do. Um, and like part of your role is to not cause like, distress. You're meant to keep patients comfortable and um, treat like, rather than actually cause them pain. Which is why that was the difficult thing, because you felt like

you weren't doing your job and did, you just weren't maintaining dignity, as much as you tried, it was really difficult."

(NURSE AS ADVOCATE, NURSE AS TRANSLATOR, SUPPORT THE FAMILY, MAINTAIN DIGNITY)

"Um, yeah I do, mostly nurses but sometimes doctors as well. Um, and I think, I do sometimes think doctors do have different opinions than nurses on quite a lot of things. Um, but I don't know whether that comes from nursing, where you're just, you are more probably patient, like, doctors are patient centred but they're also a lot more, we can sort, we can sort whatever the problem is out kind of thing. Whereas nurses are a lot more um, let's just get to grips with the basics for, like, I can't, like I know what I'm trying to say but it's not, like um, a lot more put the patient first. Which doctors do but I think doctors are a lot better at seeing the actual disease and nurses tend to see a person more, whereas doctors tend to see um, the actual thing that's wrong, that's brought the patient to us more, if that makes sense?"

(DOCTORS AND NURSES HAVE DIFFERENT PERSPECTIVES)

"Um, there's, um, let me think ... yeah, there's been, there was one where sort of like I was a bit, I was really like to the doctor, I was just like I think we should be just stop, like, reducing this and making the patient more comfortable and they, and they were saying oh what, they said they'd only been here for, she was quite an elderly lady and she was only for level, she wasn't to be escalated to level 3 care anyway. She was only for level 2 care, but she was just a bit, she was like, we have to give her, and once the doctor explained I could completely see it. She was like we have to give the um, antibiotics, we need to support her until the antibiotics have, because I think it had been two days and they wanted to give her, the doctors were like we want to give her three days to make sure that the antibiotics have got fully taken a hold and stuff. and once she explained that, that was fine. So there was differing opinions but when people explained, people explain things, I think it helps [laugh]." (EPISTEMIC INJUSTICE)

Appendix 18: Example of Theme Development

The data was analysed using a dynamic interplay of six activities for interpretive phenomenology suggested by van Manen (1990).

- 7) **Turning to the nature of lived experience**
- 8) **Investigating experience as we live it rather than as we conceptualise it**
 - I completed these first two activities by conducting the interviews, making field notes, probing their accounts, reflecting upon the interviews and immersing myself in the participant's narratives.
- 9) **Reflecting on the essential themes which characterise the phenomenon**
 - This step was carried out by reading, re-reading and coding the interviews in NVivo. An example of this coding process is show below.

decision. The psych team came, they made their assessment but wanted to come back again in a few days to do it again. And all the while, minute by minute, she still felt the same, she was still angry, she was still crying, she was still unhappy with everything that we did, and she knew...she got better at communicating with us and she knew it wasn't our fault, but it didn't help, she just didn't want to be like this anymore. So eventually...I can't remember the length of time that it took but there was certainly an awful lot of different teams that had to be involved. They had to get a lot of paperwork; proof that she was making the decision completely informed of the risk that she was taking. And then the discussions we were having with the family were also quite upsetting because you could see how torn they were over it. They didn't want her to live that way...but they didn't want to lose their Mum...either.

GM: So the discussion was for removal of the collar?

P: Yes, it wasn't that we were going to stop doing everything. She had come past the point of being particularly physiologically unstable. But we all knew that when the collar comes off and she moves, that point could come quite quickly because she was so brittle. Erm...so, I think what distressed me...it was different areas. It was the fact that she felt that way because it's not nice to see another human being feel that way and knowing that...well, to me, I always had the presumption of capacity because that's what we are told to do. She didn't seem like a confused person, she seemed to understand everything that we were telling her but yet I had to stand and do things to her that I knew she didn't want, but I from a legal perspective, I couldn't not do them. I couldn't just let things go, or open the collar or do things the way she wanted me to do them. Which to a nurse it feels wrong because you're told from day one, you know, it's about promoting your patients autonomy and you learn about consent and you know...but I felt, I didn't know if what I was doing was right because it was like, right ok I'm doing the right thing because I'm not causing direct physical harm but if I was doing what she wanted me to do then I would cause her harm. So it's this constant vicious circle of, "Am I doing the right thing? Am I actually doing the right thing?"

and it was uncomfortable. If you asked if she was in pain she said "Yes" and no matter what pain relief we gave her, it just hurt her. So this was going on for a little while and it wasn't being ignored. She had so many different teams involved in her care because of the amount of injuries that she had sustained. And it's considered that you have to get everyone on board, everyone has to come in. So we made sure it was flagged up to...myself and the rest of the nursing team made sure it was flagged up to our consultants. They went and spoke to her and from my perspective everyone was very understanding and understood where she was coming from and tried to gently talk to the family about how she was telling us she felt. She wasn't doing it with them; she wasn't saying anything or trying to communicate this to them in anyway. Maybe because she just knew it would upset them so much. So after much discussion and gentle conversation with the family, some of the family were on board, as in "Well we will do whatever she wants to do." Others were more resistant saying that, "No we need to encourage her to fight this and to keep going." But as a nurse at the bedside and working on the unit, you could see this visible distress in her and you could understand it. You know, she...and there's nothing really to do with age...there's a part of it, in a sense that, she herself was communicating to us, you know...almost like, I'm happy, I've done what I needed to do. I don't want to go through this. And she had been told that she would live the remainder of her life practically immobilised and unable to be off support. And this just caused her to become really, really distressed and upset, as it would most people. So then they had to start looking at the legal aspect of this. What she really wanted most of all, through more communication with her was for the collar to come off. It wasn't that she wanted to die she just didn't want to live with the collar on. But then we were in the position of, we need to prove she can understand the risk to her life if we remove that collar. So, there was a psych assessment, mental capacity assessments... which were difficult to organise. And this is where I think I started to become a little bit... frustrated with the process because it just seemed to take so long. So every single team had to come and review and agree with the



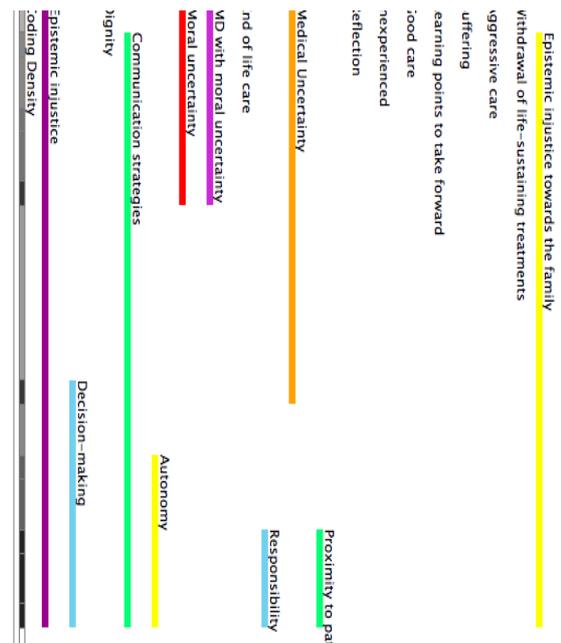
All nodes coded in transcript 1 extract:

1. Proximity to patient
2. Decision-making
3. End of life care
4. Dignity
5. Communication strategies
6. Anger
7. Emotional impact of nursing
8. Autonomy
9. Pt confides in nurse- TRUST
10. Legal obligations
11. Moral uncertainty
12. Care provided in best interests
13. Encouraging communication
14. CONSENT issues
15. Logistics increase difficulty
16. Delays in decision-making

New codes were developed up until interview 16 at which point the development of new nodes decreased and by the final interview no new nodes were being added. Although theoretically I am skeptical regarding whether data saturation is possible, this reduction in the number of codes does suggest saturation may have been reached within this sample.

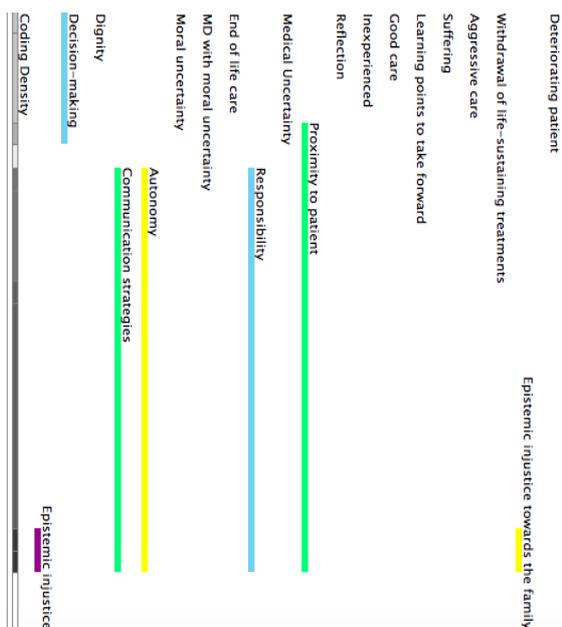
Another example of the coding process is shown below. I have selected an example in which there are shared codes between the two examples- the shared codes are in bold. When certain codes are prevalent within the data, they can be constructed into themes.

and he had like a GCS of 3 most of the time, and you know taking down all of his Propofol, we take down all of his sedation and still he's not doing anything. And oh that horrible feeling you get in your chest like, shit I know how this plays out and then you've still got that hope and I think that it's really hard not to transmit that hope to the parents and it's quite hard to explain to his partner how unsure you are. And I think that's what really distressed me because we couldn't give them any answers, I looked after him the day after he came in and then obviously he'd been in for like five days by the time I left, er, moved on to a different patient. But every time they'd be in, bang on like, bang on visiting hours and they had a lot of questions and they were obviously quite intelligent, trying to get their head around it and you do get that horrible feeling of lying to them but also trying to explain like he is a young guy, everything that we can gather actually does look really positive. But at the same time you don't want to be like, yeah, yeah he's a young guy, we see young guys bounce back all the time. But then like the patient in front of you does not look like he's bouncing back and he's showing no signs of anything... like the CT head was like, nothing on the CT head, but that's when he just came in and we have no idea what's going on and clinically he looks like he's got a huge brain injury. Er, and then I think he seized in front of them and that's, and it was, er, he, er, he had like he'd hyperextend when he seized but he'd extend his neck as well and it was like ... very exodus looking. Like it was one of those really... well no seizures are pretty... but it wasn't, it was a very, er, aggressive seizure I guess. Er, and they'd be like what did the EEG show and you're like I know what the technician told me but I can't report on that because the doctor needs to and the technician should be reporting on it anyway and but like in the back of your head you know that it showed like loads of underlying seizure activity. And I think that, the feeling like you're there as an intensive care nurse not only to give intensive care to the patients but like there's something about that being that interface that makes you feel responsible for the family and friends as well in a big way.



likely not going to get better and you're always like...someone always comes with, like comes with some sort of article with someone who was like in a coma for six years or something and comes back and now can play the piano. And you're like, oh just...like oh my God- I feel like journalists should be hunted down sort of you don't understand how much distress you're causing families nationwide, er, and "I read that this could be a really positive sign" and that all that... you know? And then they look at you... and they always seem to do this... but this particular patient his dad I got on really well with. We are both from like the same sort of place. I'm from X, they were from X, it was like we really kind of bonded and it was fine. And then the doctor came over and he had quite a good, frank conversation about how like at the moment this is what the EEG is showing and clinically he doesn't look very well but at the same time he's a very, very young man and we need to give him time, we need to give him at least a week like if not more and we have to do right by him, we have to just kind of like leave him be and make sure he doesn't get anything else. A really good conversation, I was really grateful for the doctor having that chat but then the dad turned around to me and was like, so that conversation with the doctor do you think he's telling us the whole truth? Do you like... what's your opinion of it? We want to hear it from you like you've been here with us for four days, like we want to know what you think? What do you think? And I'm just a bit like, oh I mean like it was so good that that doctor had had such a good conversation because you do see doctors and other physicians not have such good conversations. And if he hadn't had such a good conversation then I would have been in a real spot because I'd have, if I disagreed on anything or felt like he'd left some intrinsic information out... but I was like no I'm actually able to get behind it but it puts you in a really distressing situation where you understand that they're there and they're second guessing everyone and everything and they don't have a clue what is going on. And you feel like again like that horrible feeling of hiding from them, that's you're in the know and they're not.

So what did you say to them in that scenario?



All nodes coded in transcript 2 extract:

1. Epistemic injustice
2. **Decision-making**
3. **Communication strategies**
4. **Autonomy**
5. **Moral Uncertainty**
6. Responsibility
7. Medical Uncertainty
8. **Proximity to patient**
9. Epistemic injustice towards the family
10. **Delays in decision-making**

Not all shared codes (in bold) became themes because although they were shared between these two interviews, they were not prevalent across all the interviews, or deemed to be significant to explain moral distress.

10) Describing the phenomenon through the art of writing and rewriting

For each participant, I wrote a narrative in which I reflected upon my initial impressions, summarised the key experiences they described, provided my initial interpretation of their experiences and highlighted any similarities to other participants' experiences. I also listed my initial impression regarding the key words/key themes that seemed to be significant at this point. I then listed the codes that were listed in NVivo as the most commonly coded. This was interesting to provide a comparison. I also listed key quotations at this point that I thought might be useful later on to support themes.

Below is an excerpt of the narrative from 1:

I had the distinct feeling that the experiences she shared were ones that she had very specifically wanted to talk about because they had troubled her for a couple of years. As with X, Y seemed to come primed with her moral distress story and immediately stated that the issues that affect her the most are to do with end-of-life care and decision-making around that. Her narrative seemed very prepared, not in a fabricated way but rather because she had gone over the events repeatedly in her own mind. This made my job as the interviewer easier because many of the facts came very readily. Again, she was very articulate, spoke freely and provided a lot of detail. I got the impression that she was very genuine and honest and didn't feel she had to censor her thoughts for the interview in any way.

I think the fact we are both critical care nurses allowed us to build up a rapport easily through our shared experiences. She didn't have to explain complex terminology, for example, having to deflate the balloon of a tracheostomy in order to put on a speaking valve so the patient can talk. I think the ease in explanation, as with other interviews, meant that Y could speak freely knowing we had shared experiences and I knew her world, making opening-up much easier. As with X (and less directly A- because she was never explicit about her intentions), Y discussed the fact she had temporarily taken on a different role in order to get a break from clinical nursing and critical care.

Issues around consent seemed to be the crux of moral distress for Y. In her first story, she spoke about an elderly patient who had suffered terrible fractures and wanted to remove the collar which was stabilizing her spine. Y seemed very frustrated and explicitly states that what frustrated her the most were the delays and discussions around trying to assist the patient with this- the multiple teams involved in her care all needed to visit and the psych team needed to do their assessments over several days. Y found it difficult and distressing having to continue providing care for this patient when she was declining care. She felt that on a personal level she wanted to stop but professionally and legally she felt that she had to continue providing this care. She discussed the grey area of best interests and the grey areas between a patient deciding they no longer want treatment and actual treatment being stopped: *"it's that very hard grey area of best interests* and also articulates the belief that they shouldn't just stop treating the patient. These gaps are filled by nurses who are required to continue providing care until the legal team say "yes, you can stop." In this sense then Y seemed to feel that there was a way in which ethics and law conflict – the law requires that you *"dot the 'I's' and cross the 't's'"* but the right thing might have been to stop as soon as the patient stopped consenting. Ultimately, she was carrying out the decisions of others and subsequently she felt frustrated and powerless, and felt she was contributing to suffering. She seems to feel very conflicted about the right thing to do, she is aware the patient wants to discontinue but she also feels they shouldn't just stop. She seems to feel both constrained and uncertain/torn.

She discusses not knowing why things were taking so long because she had never been through this particular experience before and not knowing why

things were being done and taking so long. This raises the issue of both epistemic injustice and the importance of experience- she had not been involved in the decision-making and discussion, and she didn't know what to expect and that this fed into her feelings of powerlessness.

Beth discusses the feeling that she struggles to articulate the ethical aspects of her experiences: *"I feel like sometimes I don't have the language to be able to say it."*

Key Words/Key Themes:

(these are decided prior to identifying the most coded nodes)

CONSENT

PROXIMITY TO PATIENT

PROFESSIONAL VS. PERSONAL MORALS

ETHICS VS. LAW

FEELING DISTRESS WHEN THE 'RIGHT' THING HAPPENED

Most Coded Nodes:

1. Care provided in best interests
2. Legal obligations
3. Patient wishes
4. Proximity to patient
5. Patient confides in nurse- TRUST
6. Emotional impact of nursing
7. End of life care

Below is an excerpt of the narrative from 2:

Like A, W is planning to leave ITU for a new role but mainly because she wants a new challenge.

Also like Y, M and X, W launches straight into her moral distress stories without any warm up period. Her first story is about perceived futile care and how she sometimes feels like she is just contributing to suffering. W discusses epistemic injustice that is directed towards the family. W describes the distress that she faces because she feels she can't be honest with the family because they are awaiting official results for example.

This causes inner conflict because she feels she should tell the family but is constrained as she awaits official test results. As with Y, she talks about the need to *"cross the t's and dot the i's"* before they can tell families the bad news. I wonder if we empowered nurses with better communication skills whether this would help? Participants do discuss communication strategies that do not promote any false hope- such as painting a poor picture- but essentially, they are stuck in a very compromising position because even if they were totally honest with families, they don't know what the plan of care will then be because it isn't up to them to decide:

“I think the group of patients that really play on my mind a lot, especially within the intensive care environment, are the ones with predicted poor outcomes that we, er, we keep on the intensive care unit that we give a lot of therapy to and that more often than not don’t survive the process or become severely handicapped and both cognitively and physically disabled. I think those, as a group of patients are the ones that I often... even at work kind of just... at the end of the bed and you look at them and you’re like, what are we doing? Yeah- just why? To what end? Er, and I know that sounds quite heartless but a lot of the time doing like GCS’s [Glasgow Coma Scale] on them and you’re like really squeezing them and they’re doing a very like, they’re going into like abnormal flexion and it just, it looks grotesque, I know that you have hypoxic brain damage, I know that you’re not coming back from this. Er, and I understand the process of having to make sure and having to give it a certain amount of time before you can start to approach those sorts of conversations with family. What I find very distressing is the interim when families are asking you a lot of questions, er, results and you feel like you’re keeping this big secret from them because you know, you’re sitting there and clinically you know that this is going to be very bad but obviously you can’t tell them that because you’ve not got the EEG [electroencephalogram] back yet or like you’ve not given it a week since the three CT’s [computerised tomography]. I know that you have to cross the t’s and dot the i’s, a lot of the time I feel like I’m lying to – to families in particular because obviously the patient’s not talking, you’re kind of their interface of the world and you feel like you’re doing them a bit of a disservice a lot of the time. I think that’s the group of patients that causes me quite a lot of – quite a lot of distress.”

Looking back, I can see this theme in some of E’s narrative too- although E is coming from the perspective that often the healthcare professionals are in the know and the families aren’t because of the Consultants poor communication skills and not making things clear enough or not being honest enough about the prognosis. E describes wanting to tell families when care seems to be futile and that she doesn’t know where she stands legally and fears conflict with the Consultants.

Whereas W describes it as if the team are more purposively keeping things from the family:

“...you’re looking and you know what’s going to happen and the doctors know what’s going to happen and the only people that don’t really know what’s going to happen is the family. And so all the professionals in the situation are kind of able to come to like a mutual understanding so they’re all on the same page when the conversation is put forward.”

W describes a situation where despite the fact the doctor had been very clear and honest with the family, the family still asked her what she thought and whether she thought the doctor had been honest. This shows the level of trust that can be built between the nurse and family but W just sees it as an added frustration because she didn’t know how she would have dealt with

the situation had she disagreed with the doctor. She believes it is important that the healthcare professionals show a united front to the family whereas E felt like her responsibilities lay more with telling the family the truth but feared the repercussions/retribution.

W feels like it's important the family think they are making the decision, whereas E expressed the belief that the family should be relieved of the feeling that they are responsible.

W is very aware of her responsibilities and has more of an awareness of the 'microethics' - the everyday ethical issues:

“but that will always terrify me that ultimately the tiny decision of me getting annoyed with an alarm, choosing to pause that alarm which pauses all of them for two minutes that could have been two minutes where she would have been in SVT and not getting her like output. And – and that – that responsibility no matter where it came from, whether it came from ignorance or – or it's still my responsibility at the end of the day...”

She talks about repositioning patients when they say they don't want to be, and yet we do it anyway because we are doing it in their 'best interests' - we are making all of these small decisions for them and this makes W feel uncomfortable. She sees the repositioning option as the *“lesser of two evils.”*

Key Words/Key Themes:

(these are decided prior to identifying the most coded nodes)

INTERACTIONS WITH THE FAMILY

EPISTEMIC INJUSTICE TOWARDS THE FAMILY

ETHICS EDUCATION

IMPORTANCE OF LEARNING FROM moral distress AND MISTAKES

Most Coded Nodes:

1. Good care
2. Inexperienced
3. Moral uncertainty
4. Medical uncertainty
5. Responsibility
6. moral distress with moral uncertainty

Examining the most coded nodes and those that I initially listed as key words/themes, the reader can see there is often a discrepancy between the two. This is where the balance needs to be struck between those mentioned most frequently and those interpreted as the most significant. Paley (2017) is critical of qualitative researchers for polarising qualitative vs. quantitative. He highlights how qualitative researchers use quantitative terms, such as 'many' and 'most'. Herein lies the difference, a qualitative researcher doesn't simply choose the themes based on the most frequently coded nodes but rather balances frequency and importance. NVivo is used as a tool for analysis, the researcher is not a slave to it.

11) Maintaining a strong and orientated relation to the phenomenon

I re-wrote the findings chapter several times because I realised that in the first few iterations I was not focusing enough on the actual phenomenon of moral distress and instead I was exploring all the external factors that affected moral distress experiences. Many of these themes became the compounding factors that I discuss in chapter 6.

To maintain focus on the phenomenon, I tried to explain what I perceived to be as the 'crux' of moral distress for each participant in each of the experiences they described in their narratives.

The moral distress crux from narrative 1:

MORAL DISTRESS:

- **INNER MORAL CONFLICT, MORAL UNCERTAINTY AND DOUBT; compounded by feelings of powerlessness and responsibility.**
- The crux of the moral distress seemed to be that Beth had to provide care to a patient who wasn't consenting because they were awaiting formal assessments to withdraw life-sustaining treatments.
- Legally they had to fill in the forms which was time-consuming, professionally she had to continue to care for the patient and carry out interventions that weren't being consented to and personally, she felt that this was wrong= INNER CONFLICT.
- Supports a Jameton-like definition because she had an idea of the 'right' thing to do
- But she can't be said to know with certainty because she also felt uncertain about what the right thing was- she felt conflicted about whether following the rules and getting the paper work done and providing care in the interim was right or not.

"I think what distressed me...it was different areas. It was the fact that she felt that way because it's not nice to see another human being feel that way and knowing that...well, to me, I always had the presumption of capacity because that's what we are told to do. She didn't seem like a confused person, she seemed to understand everything that we were telling her but yet I had to stand and do things to her that I knew she didn't want, but from a legal perspective, I couldn't not do them. I couldn't just let things go, or open the collar or do things the way she wanted me to do them. Which to a nurse it feels wrong because you're told from day one, you know, it's about promoting your patients autonomy and you learn about consent and you know....but I felt, I didn't know if what I was doing was right because it was like, right ok I'm doing the right thing because I'm not causing direct physical harm but if I was doing what she wanted me to do then I would cause her harm. So it's this constant vicious circle of, "Am I doing the right thing? Am I actually doing the right thing?" And all the form filling and the...I knew it all had to happen...it had to happen in order for this to be done properly but that takes time and in a big system with a lot of teams, a lot of consultants, a lot of paperwork..."

- As with A, the moral distress story involved the ability to provide a ‘good’ death- it seems that the belief that a ‘good’ death is possible is central to nursing. As with A, the right thing (in Y’s mind) ultimately happened- they took the collar off the patient and she had a ‘good’ death a few days later- but the way in which this happened caused distress, frustration and anger as she went against the patient’s wishes in the interim period. In an ideal world, Y says this would have been done quicker. ***“I was doing the right thing, I just felt bad about the process”.***
- In the second story—she is again very conflicted about the right thing to do- the patient has just told her that she doesn’t want to be in ITU, dependent on a ventilator but the patient doesn’t have a DNAR- there is again a conflict between personal vs. professional responsibility and ethics and law- legally she has to resuscitate the patient.
- As with A, it seems that it is possible to feel morally distressed even when you think that the right thing has happened: ***“...it's always, well to me it's always that conflicting feeling of, we did a good thing but why does it feel so bad.”***

The moral distress crux from narrative 2:

MORAL DISTRESS:

- Constrained moral judgements- wants to tell families the ‘truth’ but can’t until they have more definitive answers- constrained by awaiting test results, or the doctor to inform them- epistemic injustice.

“...that feeling that you’re not doing right by the patient by not being honest [with the family] but at the same time definitely not being able to put all the cards out there and be part of – part of yeah you get a horrible feeling that you’re lying, that you’re holding, well you are you’re holding information back but you know why and you know that you’re trying to protect them from information that’s not conclusive. But at the same time you’re looking and you can’t know what’s going on inside that patient, you can’t know if they’re in pain or not, you can’t know if they’re what are we doing, we look like we’re causing you loads of suffering sticking tubes in you and sticking needles in you and squeezing you every single hour and shining lights in their eyes and constantly putting you into like huge machines and we’ve got no idea if they have any sort of awareness.”

“...and there’s the other side to it where you just feel like you’re not doing the right thing with those sorts of patients and I think that comes through when they are maybe older or have had really traumatic injuries...er... where beyond... you are beyond any doubt that this is going to turn out very poorly.”

- W seems to make some ‘moral judgements’ - ie, that care is futile but she is very aware of the nuances and she finds it difficult to feel certain - there is often an element of uncertainty:

“I think, I think for me it comes out of, er, a feeling of emotional or physical distress when you either don’t feel like the right decision, well you feel like you followed a course of action or been complicit in a course of action which wasn’t the correct one or where you are unsure as to whether it was the correct one, I think it can be either or, er, where yeah that’s what I would, where you’re either faced with the decision or you’ve already done it and you are thinking that wasn’t right or I don’t know whether that was right or I think it was right but I can’t be 100% sure. It happens all the time because you can never be 100%, er, yeah that’s what I’d say it was.”

- Inner conflict (role of a nurse is to alleviate suffering but often she is contributing to suffering where the care is futile) compounded by moral uncertainty:

“So I think the distress comes from that rock and a hard place and that’s definitely the crux of it it’s like I don’t feel comfortable standing here and it’s been months and month and months and just I feel like I’m dragging out this family’s pain and I may be dragging out your pain to like what end... and why are we doing this? And this doesn’t seem right and this doesn’t seem fair or nice. But on the other side you’ve got what feels like sometimes a little bit of a like educated guess and it’s just like oh and there, and you’re just like you’re faced with that either or which often is an either or, those are the ones that pop up in the night you know those are the faces where you’re just a bit like.... I think a lot of the time, I’ve never been in a situation where I don’t feel like we haven’t made the right choice but I’ve definitely, definitely been in the situation where I’ve spent a lot of time questioning it and yeah it’s that rock and a hard place, it’s that gamble on someone else’s existence, well it is you’re gambling on their existence and what state that existence will be.”

- The latter half of this quotation W, as with A seems to suggest that moral distress can occur even when your feel the right thing happened.

To try and make sense of the many factors which seemed to contribute to moral distress, and the effects of moral distress, I constructed a table of causes and effects. This helped me to think about the process of moral distress in a more systematic way.

Causes of Moral Distress	Effects of Moral Distress
<ul style="list-style-type: none"> - INTERNAL: - Inner moral conflict (about what is the 'right' thing to do) - Uncertainty - Belief in moral relativism – there is no ONE right thing, it is relative to the scenario, patient and family preferences. - Professional vs. personal morals- ROLE MORALITY - EXTERNAL: - End of life care- withdrawal of life-sustaining treatments. - Constraint- continued suffering. - Perceived futile care - Quality of life judgements 	<ul style="list-style-type: none"> - Sadness - Frustration - Anger - Feeling numb and used to death - Feeling troubled - Indirect effect-going into a different healthcare profession.
<ul style="list-style-type: none"> - INTERNAL: - Inner moral conflict - Uncertainty, doubt - Feelings of powerlessness - Feelings of responsibility - Professional vs. personal morals- ROLE MORALITY - EXTERNAL: - Constraint - providing care in interim whilst assessing patient's capacity to decide for removal of life-sustaining treatment. - Issues of consent- continuing care in interim period. - Conflict between law and ethics - Participating in suffering - Carrying out others' decisions 	<ul style="list-style-type: none"> - Anger - Frustration - Guilt
<ul style="list-style-type: none"> - INTERNAL: - Constrained moral belief - Uncertainty- there is no right or wrong so cannot be right- belief in moral relativism - Inner moral conflict - Feelings of powerlessness - EXTERNAL: - Futile care - Poor quality of care 	<ul style="list-style-type: none"> - Exhausting - Frustration - Anger - Nightmares, difficulty sleeping- but more an effect of general stress starting on ITU than necessarily moral? - Compassion fatigue

<ul style="list-style-type: none"> - INTERNAL: - Constrained moral judgement (there is inner moral conflict but no uncertainty) - Feelings of powerlessness - Feelings of responsibility - Feeling of causing suffering (goes against nursing values) - Inner moral conflict- participating in something that feels wrong but having to do so because its' your job (personal vs professional morals?) - EXTERNAL: - Futile care - Poor communication - Uncertain about what to say to the family - Participating in suffering 	<ul style="list-style-type: none"> - Upset - Frustrated - Angry - ? Moral residue/ residual feelings...

I then compiled a table of each 'crux' which through further interpretation, reflection, analysis and discussion became the moral events that I concluded cause distress.

Moral Distress	Compounding Factors
Inner moral conflict (about what is the 'right' thing to do)	<ul style="list-style-type: none"> - Reconciling 'hospital' morals with 'normal' morals - Uncertainty - Belief in moral relativism
Inner moral conflict	<ul style="list-style-type: none"> - Uncertainty, doubt - Feelings of powerlessness - Feelings of responsibility
Constrained moral belief (? Terminology, belief or judgement, if there is uncertainty, should it be a belief?)	<ul style="list-style-type: none"> - Uncertainty - Inner moral conflict
Constrained moral judgement (there is inner moral conflict but no uncertainty)	<ul style="list-style-type: none"> - Feelings of powerlessness - Feelings of responsibility - Feeling of causing suffering - Inner moral conflict- participating in something that feels wrong

From the 'crux' of moral distress, I was able to construct the final themes that made up the moral events and the predominant emotions associated with distress. I went back to the narratives to explore the causal criteria and found that proximity, responsibility and empathy all came through as prominent themes, explaining how participants felt connected to moral events.

12) Balancing the research context by considering parts and whole

To try and explain how moral distress relates to its constituent parts and the compounding factors and other concepts such as compassion fatigue, moral residue and moral failure, I constructed a mind map. This required me to take a step back and look at the way in which participants had described their responses to moral distress and how this related to other concepts found in the data. The mind map went through many different iterations before it became the moral distress model that is not included within the thesis as a tool to explain the phenomenon.

From the nodes listed in activities 3 and 4, the following became key themes and were determined to play the following role with the moral distress model construct.

- Proximity to patient – identified as crucial for the causal criteria.
- Professional vs. personal morals/responsibility- identified as crucial for the causal criteria.
- Emotional impact of nursing – contributes to feelings of empathy within causal criteria and exacerbates effects of moral distress.
- End of life care- common cause of moral events.
- Epistemic injustice towards the family – compounding factor- both exacerbates and causes moral distress.
- Ethics education – lack of ethics education reported as contributing to lack of confidence in moral judgements/ reluctance to make judgements/ unprepared to deal with moral events.
- Moral uncertainty- commonly reported moral event that causes moral distress.
- Medical uncertainty- difficulty on prognostication – contributes to moral uncertainty.