An Interdisciplinary Exploration of Moral Distress in Healthcare Providers (HCPs) Caring for Patients Requiring Long-term Ventilation

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Abstract

Introduction – Moral engagements are a deeply inherent and intractable component of modern healthcare practice. Challenges arise when there are multiple core values conflicting, often in an emotionally charged, confusing, and at times frightening environment. These challenges affect not only healthcare providers (HCPs) but also patients and their loved ones, healthcare organizations, and the wider community. When these ethical uncertainties, conflicts, and dilemmas are unable to be resolved satisfactorily moral suffering ensues.

Moral distress is a particular form of moral suffering. Moral distress is defined as the suffering experienced because of situations in which HCPs are aware of a moral problem, assume moral responsibility for the issue, and subsequently make a moral judgment as to what they believe is the right word or action to take (or not take). However, due to internal or external constraints, real or perceived, the HCP feels they cannot act on their beliefs. The HCP then sees themselves as compromising their personal and/or professional values resulting in the phenomenon of moral distress. This moral distress may be experienced as guilt, shame, helplessness, anger, frustration, and powerlessness. There is a significant correlation between moral distress and the HCP's emotional, physical, and spiritual well-being.

Purpose of research – The purpose of this research is to explore the phenomenon of moral distress, through an interdisciplinary research lens, looking at the whole multidisciplinary team caring for patients requiring long-term ventilatory support. These HCPs were drawn from the disciplines of nursing, clinical management, medicine, pharmacy, respiratory therapy, physiotherapy, spiritual care, and social work. This study is unique in exploring moral distress in this population and environment.

There are many shared sequelae, symptoms, and concepts, such as powerlessness, shame, helplessness, courage, guilt, forgiveness, and non-acceptance, in the moral suffering of the alcoholic and the moral suffering of the HCP. What insights might we learn from the sufferer recovering from alcoholism who is practicing 12 Step spirituality and the HCP living with moral distress? The possible application of 12 Step spiritual principles and practices in dealing with and healing from moral distress will be explored. Deepening our understanding of moral distress may be crucial in developing effective remedies to mitigate the causes of moral distress, facilitate healing, and promoting moral resilience in our HCPs and healthcare organizations. Thus, the participants were encouraged to share their experience not only of moral distress but also how they personally made sense of and dealt with moral distress. Furthermore, they were given space to provide answers to what works at an organizational level to mitigate, process, and heal from moral distress.

Methodology – An interpretative phenomenological research method was employed. This method allowed an in-depth exploration of the HCPs' lived experience and parallels in literature with the interdisciplinary research method. It was a method ideally suited to exploring the issue of moral distress through the subjective lived experience of the phenomenon. The Measure of Moral Distress for Healthcare Professionals (MMD-HP) validated questionnaire was completed and in-depth interviews undertaken to obtain a clear understanding of the person's lived experience of the phenomenon of moral distress.

Findings & Discussion – Multiple professional perspectives were obtained from the HCPs working on the unit. Two of the HCPs left the unit due to moral distress. Their testimony was rich, powerful, and furthers our understanding of moral distress in these various healthcare professions. Evidence informed personal and organizational suggestions, based on the HCP's lived experience, are offered for dealing with and healing from moral distress. This research uniquely uncovers and highlights the epistemological and ontological difference between powerlessness and helplessness as experienced by HCPs on a long-term ventilation unit. It will be vital that we differentiate between these two concepts when discussing and treating moral distress in HCPs.

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These are my final typed words of this PhD manuscript. It has been an incredible journey since I commenced the graduate diploma in Catholic bioethics in 2019 (with a century defining pandemic thrown in for good luck).

I am eternally grateful to the God of my misunderstanding that has ultimately allowed me to “climb my Everest,” guided me to seek those who have loved and healed me, and given me a second chance at life. To all those anonymous healers – thank-you. I will pay it forward.

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Chapter 1. Introduction

1.1. Purpose of Research

The purpose of this research is to explore the phenomenon of moral distress, a particular form of moral suffering, through an interdisciplinary research lens, looking at the whole multidisciplinary team caring for patients requiring long-term ventilatory support.[a] What would the lived experience of each of these healthcare providers (HCPs) be in relation to the potentially morally distressing workplace situations they encountered? What would the similarities and differences of experience of moral distress be across different health professions? An interpretative phenomenological analysis (IPA) focusing specifically on the lived experience of the whole healthcare team allowed an in-depth exploration of the HCPs' exposure to, understanding of, and how they made sense of their moral distress. This study is unique in exploring moral distress in this population and environment.

This research will predominantly be viewed through the lenses of 12 Step spirituality and virtue ethics. There are many shared symptoms, sequelae, and concepts, such as shame, powerlessness, acceptance, helplessness, forgiveness, and hopelessness found in the moral suffering of the HCP in moral distress and the moral suffering of the alcoholic practicing 12 Step spirituality.[2,3,4,5,6,7,8] The possible application of 12 Step spiritual principles and practices to healing from the effects of moral distress will be explored. 12 Step spirituality and virtue ethics are two sides of the same coin, as virtue ethics explains the what and why, and the 12 Steps show one how.[9]

How HCPs and their workplaces might cultivate moral resilience and restore their moral integrity will be explored and an overview of what the moral in moral distress may refer to will be presented. Deepening our understanding of moral distress in these HCPs will be crucial in developing effective remedies to mitigate the causes of moral distress,

[a] Long-term ventilation (LTV) patients are clinically defined as those patients suffering from severe respiratory impairment who no longer require the services of an acute care facility, such as an intensive care unit. Typically, they require ventilator support for more than 6 hours per day and for more than 21 days. Their overall health status is stable, and they are no longer acutely or critically ill.[1]

facilitating healing, and promoting moral resilience in our HCPs and healthcare organizations.

Why this research and why now?

1.1.1. Background to this Research

My career in healthcare began as a teenager in Yorkshire, England with a simple desire to help others and make a difference in their lives. Since then I have been fortunate to practice in England, Bermuda, and Canada, and to gain experience in several specializations in hospital, research, and community settings. Much has changed in healthcare over that time but my simple desire to make a positive difference in the lives of others has never wavered. It still motivates me in my professional life today and it underlies my present ambition in undertaking this research exploring moral distress in our HCPs.

Whilst working in cardiac nursing my passion for clinical ethics was piqued. It was in the cardiac device clinic that I was blessed to work with world class researchers and clinicians, dealing with the complexities and challenges of end-of-life care. There was a case that resulted in a profound moral injury to me. Moral injury, though on the same spectrum of moral suffering as moral distress, displays some distinguishing features that include a profound threat or violation of one's moral foundation and conscience.[10] This often occurs after a severe personal, organizational, or leadership transgression. Moral injury may lead to an erosion of one's moral identity generating profound feelings of guilt, shame, or unworthiness.[11] Unfortunately, at that time, I had no awareness of what moral injury was, and how to process and heal from it.

In 2018 I moved to a Catholic healthcare organization working in Nursing Professional Practice and education. I was invited to join the hospital ethics advisory committee, and it was there I was fortunate to meet my supervisor and mentor Dr. Hazel Markwell and then enrol for a graduate diploma in Catholic bioethics.

Whilst undertaking the bioethics diploma the COVID-19 pandemic hit our healthcare systems. I had an upfront seat to witness the confusing and frightening events firsthand. Initially unsure of what they were facing, with no vaccines, limited personal protective

equipment (PPE), and no more family support at the bedside, the staff did the best they could with what they had. I could hear and see that the HCPs were traumatized. It was at this point I started to become familiar with the concept of moral distress. Moral distress was something that I had previously experienced myself yet was not fully aware of, nor had clearly articulated. I now believe it strikes to the very core of our human beingness and has a profound negative impact on our HCPs, patients, hospitals, and wider communities.

I wanted to understand what moral distress is and how it affects our carers, patients, families, and organizations. Following the completion of the graduate diploma I was supported by Dr. Markwell to commence this research. Through this research we hoped to learn what we can do to improve our systems to reduce the incidence and severity of morally distressing situations, and to help our HCPs deal with and manage moral distress.

Finally, as an HCP it is always of crucial importance to ask how this research might impact the care of the patient. One of the most significant predictors of a positive patient experience is the health & wellbeing of the people providing care to them.[12] NHS England have shown a direct link between staff wellbeing and patient safety. Their research highlighted the necessity for staff to be provided the support, space, and time to enable them to provide safe, high-quality care. Furthermore it highlighted how a healthy organizational culture and positive patient safety are inseparably related. Thus an organizational culture that values, supports, and engages staff in the workplace will lead to safe, high-quality care.

1.1.2. Introduction to Chapter One

This chapter will present the background to this study of moral distress in HCPs caring for patients requiring long-term ventilation. It will review what morality refers to in the moral of moral distress and how we might know right from wrong. Predominantly it will look at this issue through the interdisciplinary lenses of 12 Step spirituality, virtue ethics, and peripherally psychology. The reason for this approach is that an interpretative, phenomenological, interdisciplinary research method could reveal a new and deeper

understanding of moral distress. It will also explore how HCPs and their workplaces might cultivate moral resilience and restore their moral integrity.

Moral distress has now been shown amongst many HCPs, including nurses, physicians, respiratory therapists, pharmacists, psychologists, social workers, nutritionists, and chaplains.[13] Though there appears to be differences between professions in what causes moral distress and in how it presents, it is vital that this is understood to be a multidisciplinary problem. I believe that for potential solutions to this complex multidisciplinary problem to be effective, an interdisciplinary research approach will prove beneficial.

Furthermore, we will see that the phenomenon of moral distress extends outside HCPs and is seen in veterans of the armed forces. Some authors have gone so far as applying the concept of moral distress to sufferers of alcoholism.[2]

It is crucial to be clear about the primary concepts we are referring to in this research. Having a shared understanding of the terms that will be used throughout the thesis is vital, both for the reader and for the researcher. Definitional clarity will now be provided regarding some common concepts that will be explored and utilized in this thesis to ensure we have a common and shared understanding of these terms. The following exploratory definitional parameters offer only a superficial and narrow description of some of the important terms we will be discussing. In the following chapters these concepts will be expanded upon, critiqued, and it will be shown how these terms are not fixed and static, but fluid and organic, as our understanding of moral distress has developed and deepened over time.

1.1.3. Suffering

As moral distress is a very particular form of moral suffering, what is suffering? It is something we are all familiar with. C-3PO, the wise android in Star Wars, knows that… "we seem to be made to suffer. It's our lot in life."[14] Suffering is a fundamental aspect of the human condition, with no person immune. Suffering is the First Noble Truth of Buddhism. The Buddha's goal and purpose was to understand and free himself from this suffering and its consequences, and to help others free themselves.[15(p22)] John Paul

Il writes that suffering is something which is wider than sickness, yet more complex, and at the same time deeply rooted in humanity itself, with physical suffering present when the body is in some way sick, whereas moral suffering is soul pain.[16] All of us will experience some hardship that gives rise to various types of suffering throughout our lives. This suffering is highly personal and contextual, and will be processed in many ways dependent upon a person's capabilities and resources.[17(p9)]

Although frequently used interchangeably and adjoined, for the purpose of this thesis pain and suffering are treated as distinct phenomena. Pain is the physiological manifestation of bodily injury and may be influenced by behavioural dispositions, cultural, and educational factors.[18] Suffering is defined as an unpleasant or anguishing experience, severely affecting a person at a spiritual, psychophysical, and existential level.[18] Four theological themes of suffering have been proposed; retributive which examines God's relationship to suffering; educative which looks at our responses to suffering, such as resiliency and growth; redemptive which pertains to salvation and grace; and eschatological which studies hope and a future free of suffering.[19(p12-13)]

Much of our suffering stems from the human minds seemingly inherent incapability to live in the Now.[20] The futility of non-acceptance of reality and not living in the present moment is brutally articulated by Schopenhauer:

> "We are always living in expectation of better things, while, at the same time, we often repent and long to have the past back again. We look upon the present as something to be put up with while it lasts and serving only as the way towards our goal. Hence, most people if they glance back when they come to the end of life, will find that all along they have been living ad interim; they will be surprised to find that the very thing they have disregarded and let slip unenjoyed was just their life – that is to say it was the very thing in the expectation of which they lived."[21(p36-37)]

Here and now, the very thing we avoid, is the only place and time we can heal from our suffering.[22] The only way past our suffering, is through our suffering.[23] And so we must come to know our suffering. What then is the suffering of moral distress?

1.1.4. Moral Distress and Moral Injury

Moral distress in healthcare is a unique and particular form of moral suffering. Moral conflicts are a deeply inherent and intractable component of modern healthcare practice, oftentimes resulting in moral distress. These challenges affect not only HCPs but also patients and their loved ones, organizations, and the wider community. They arise when there are multiple core values in conflict, often in an emotionally charged, confusing, and at times frightening environment. When these ethical uncertainties, conflicts, and dilemmas are unable to be resolved satisfactorily moral distress ensues.[10]

Jameton's 1984 seminal definition of moral distress as arising… "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action,"[24(p6)] has received significant critique and expansion, by both Jameton himself, and others.[25,26,27,28] Moral distress occurs when one experiences a moral situation, makes a moral judgment, faces institutional and legal constraints, performs (in their view) moral wrongdoing, and moral suffering ensues.[29] For the purpose of this thesis moral distress is loosely defined as the suffering experienced because of situations in which HCPs are aware of a moral problem, assume moral responsibility for the issue, and subsequently make a moral judgment as to what they believe is the right word or action to take (or not take). However, due to personal or external constraints, real or perceived, the HCP feels they cannot act on their beliefs, hence the conflict. The HCP then sees themselves as compromising their personal and/or professional values resulting in the phenomenon of moral distress.[26] This moral distress may be experienced as guilt, helplessness, shame, anger, and feelings of frustration and powerlessness.[30] There is a significant correlation between moral distress and intention to leave the workplace, burnout[b], and the HCPs physical, spiritual and mental well-being.[13]

One reason studying moral distress in HCPs is important is that if the moral distress is persistent and/or repetitive, or the HCP experiences a particularly morally traumatic

[b] "The term 'burnout' was first used in a clinical sense in the early 1970s by Herbert Freudenberger, a practicing American psychologist… and is defined as a condition of physical and mental exhaustion pertaining to caregiving activities and arises from chronic exposure to interpersonal stressors at work."[31]

event, then moral injury may occur.[32] Moral injury in healthcare is an experience of serious inner conflict and wounding arising from a particularly grievous moral transgression by the HCP.[33(p66)] In contrast to moral distress this morally injurious threat to the HCP's integrity becomes an actual violation that erodes their moral core, often times resulting in significant shame, and fear of discussing the experience. There is a large body of work from the military population studying moral injury and how to heal from this moral wound or trauma[c], beginning with the American psychiatrist Jonathan Shay's work treating Vietnam veterans.[34]

It is also vital to state what moral distress and moral injury are not. They are not post-traumatic stress disorder (PTSD). Moral injury and PTSD may both have known causes, specifically a traumatic occurrence. The client may have both PTSD and moral injury, or only one, with each potentially expressed as guilt, shame, anger, and a loss of trust in other people, and… "empirical studies have shown that those who score higher in reports of moral distress are more likely to score higher on validated instruments to detect and diagnose psychiatric morbidity."[36(p1)] Moral injury and moral distress may be distinguished from PTSD because they transcend the psychological to comprise the values, morality and spiritual beliefs of the individual. As Shay states… "My sense is that this is a fundamentally religious issue. It's possible to package it as a mental health issue, but I think we lose out. Even people who have had good secular treatments for their trauma still feel a need for the religious dimension of it. I don't think as a society we're offering it."[37(p1)]

A fundamental characteristic of the human being is our conscience, which guides us in navigating the moral field of human life. The very term "human-being" points to the mystery of Spirit made flesh. Moral injury and moral distress scrambles our internal compass that discerns right and wrong, good and bad.[38] Moral distress and moral injury are not compassion fatigue, typical workplace stress, burnout, avoidance of challenging situations or work, disagreements amongst colleagues, or a psychological diagnosis.[39] Nor is moral distress, as highlighted by Jameton in his initial definition, a moral dilemma

[c] The word trauma comes from the Greek for wound. The etymology of the word innocent is derived from Latin and means without wound, or if you will, the untraumatized.[35]

or moral uncertainty.[24(p6)] For moral distress to be present there *must* be a component of morality.[25]

12 Step spirituality and virtue ethics are the two main lenses that this research is viewed through. In the next two sections a brief glossary of virtue ethics and 12 Step spirituality are provided for the reader. These concepts will be expanded upon later in this chapter.

1.1.5. Virtue Ethics

Virtue ethics will be one of the lenses through which this study is viewed. Contemporary virtue ethics flows from the Aristotelian comprehension of virtues and character, and broadly speaking, theoretically accentuates the role of virtue and character in moral philosophy as opposed to utilitarianism or consequentialism.[40]

Virtues are habits that with time and practice develop into a person's character. Through consistent application and experience an individual may develop the virtue of courage and eventually become a courageous person in most environments. "Furthermore, a person who has developed virtues will be naturally disposed to act in ways that are consistent with moral principles; the virtuous person is the ethical person."[41(p2)]

Inherent in the development of virtues is the necessity of community. As Donne so beautifully articulates, no man is an Island. Thus, our character will be highly influenced by our environment and communities, including religious or spiritual groups. One such community could be a 12 Step Fellowship. The foundation of relational ethics rests on the spiritual axiom that no individual is isolated, but rather an interconnected part of the broader human race. Science continues to confirm the ancient intuitions of the prophets and mystics. Science now reveals that everything in the universe is deeply connected and linked, even light itself, which was the first act of creation (Genesis 1:3) and it is the illusion of the post-modern materialistic and rational mind that there exists an autonomous self which is the first and the true Seer.[42]

The 12 Steps are a core set of ideas and practices shared by many spiritual traditions and were chosen for this research due to the author's in-depth experiential and academic knowledge of them. Their successful application in dealing with and healing

from powerlessness, non-acceptance, shame, helplessness, guilt, and hopelessness, the very feelings felt in moral distress, lent them particular relevance.

1.1.6. 12 Step Spirituality

12 Step Spirituality will be the other lens through which the research is conceptualized. 12 Step spirituality's success in dealing with and healing from powerlessness, non-acceptance, shame, helplessness, guilt, and hopelessness,[3] those very same feelings experienced in moral distress, provided the rationale for their use in this research.

The 12 Steps **(Figure 1)** are a spiritual program for daily living based on the 12 Steps of Alcoholics[d] Anonymous (AA). Huxley believed the 12 Steps to be a part of the "perennial philosophy," or a core set of spiritual practices and beliefs shared by many religious traditions.[43] For the alcoholic the 12 Steps and their spiritual principles have one fundamental purpose; that is to bring about a transformation, or spiritual awakening, sufficient to expel the obsession for alcohol and allow the sufferer to become joyous, free, and integrated, one day at a time.[44(p15)] Importantly, they give the person simple tools for dealing with those sequelae, such as shame, non-acceptance, powerlessness, lack of insight or self-honesty, that keep one stuck in their suffering. For example, in practicing to be less dishonest one will slowly back up into honesty, and over time one will develop the virtue of an honest character. Fundamentally, virtue ethics and 12 Step practices are two sides of the same coin.[9] The community of AA, called the Fellowship, though far from perfect, is indispensable context for a wise and sustained spirituality.[45] The importance of community in dealing with moral distress will become more evident in Chapter Four and Chapter Five of this thesis.

Now the reader has an understanding of the main themes and scaffolding that will be used in this thesis, the remainder of this chapter will expand upon these concepts. Specifically –

1. What is the moral in moral distress and where do we get our moral sense from?
2. What are virtue ethics and 12 Step spirituality?

[d] Throughout the text, though I will tend to use the terms "alcohol," "alcoholic," and "alcoholism," the concept can be extended to include all chemical addictions and all substance-dependent people.

3. What can 12 Step spirituality and virtue ethics teach us, particularly in relation to the symptoms and sequelae of moral distress such as powerlessness, shame, fear, hopelessness, guilt, helplessness, and powerlessness?
4. How might 12 Step spirituality and virtue ethics provide insights and tools for dealing with, and healing from, these sequelae and symptoms?

Service Material from the General Service Office

THE TWELVE STEPS OF ALCOHOLICS ANONYMOUS

1. We admitted we were powerless over alcohol—that our lives had become unmanageable.

2. Came to believe that a Power greater than ourselves could restore us to sanity.

3. Made a decision to turn our will and our lives over to the care of God *as we understood Him.*

4. Made a searching and fearless moral inventory of ourselves.

5. Admitted to God, to ourselves, and to another human being the exact nature of our wrongs.

6. Were entirely ready to have God remove all these defects of character.

7. Humbly asked Him to remove our shortcomings.

8. Made a list of all persons we had harmed, and became willing to make amends to them all.

9. Made direct amends to such people wherever possible, except when to do so would injure them or others.

10. Continued to take personal inventory and when we were wrong promptly admitted it.

11. Sought through prayer and meditation to improve our conscious contact with God *as we understood Him*, praying only for knowledge of His will for us and the power to carry that out.

12. Having had a spiritual awakening as the result of these steps, we tried to carry this message to alcoholics, and to practice these principles in all our affairs.

The Twelve Steps are explained in the book *Alcoholics Anonymous*.

www.aa.org

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Figure 1. The 12 Steps of Alcoholics Anonymous[44]

1.2. Morality & Moral Sense

Prior to expanding on the concepts of morality and moral sense it will be vital to clearly illuminate what one is referring to when using the terms moral and ethical.

Though only a very small part of Jameton's book that coined the term moral distress specifically addresses moral distress, his book does provide an excellent overview of the field of ethics and morality in nursing and healthcare.[24] It provides a comprehensive, in-depth look at these issues and is still very relevant today. In fact, in many ways perhaps more relevant today as many of the issues Jameton discusses are just as pressing, if not more, in the contemporary healthcare environment. Reading the first chapter which begins with "The Crisis in Healthcare" it's easy to forget (and saddening) that the book was written 40 years ago.

In the same book Jameton expands on some ontological and epistemological differences regarding ethics and morality. He sees morality as referring to a set of values or principles to which an HCP is personally committed. These moral values or principles may be formal or informal, explicit, or implicit. He gives the example of some personal moral principles such as the golden rule "Do unto others as you would have them do unto you," and "Always act lovingly." Morality may refer to principles and values to which HCPs are committed to and would be relevant to their understanding and experience of moral distress. These principles may include both professional and personal commitments. Ethics, on the other hand, refers to the systematic study of principles and values, i.e., the theories and research by which one may inquire and critique, allowing us to perhaps revise and change our morality. Primarily for Jameton, and for the framework used in this paper, ethics is the more formal and theoretical term, morality the more informal and personal term.

It will be crucial then that we have a deeper understanding of what morality and moral sense imply.

1.2.1. Moral Sense

Without knowing what we mean by "morality," we would not know how to explain how morality develops and what is happening in moral distress.[46] If moral distress is

generated when we believe we know what the right thing to do or say is, yet we're unable or unwilling to, just how do we know? What is that moral sense in the human psyche or conscience that knows right from wrong? To develop a coherent argument and thesis exploring moral distress it will be necessary for one to have an understanding of moral sense, and its genesis and development.

Moral sense, our sense of what is right and what is wrong, can be examined from both a psychological and spiritual perspective. Psychologically the debate often centers around the question of whether we are born with moral sense or whether it is culturally programmed. i.e. is it nurture or nature?

1.2.2. Nurture – v – Nature

> "[T]he Author of Nature has determin'd us to receive… a Moral Sense, to direct our Actions, and to give us still nobler Pleasures."[47] Hutcheson

Limone's systematic review looks at the question of how we have a sense of morality from a psychological perspective.[48] It sees moral sense as a complex construct that evolves under the influence of one's environment, culture, and primary caregivers, and is influenced by one's character at birth and genetics. Just how this moral sense emerges and develops has challenged many researchers to attempt to articulate and comprehend the development of our moral sense. As Limone writes it is difficult to try to comprehend morality clearly, and a conclusion on whether morality is natural or socially developmental remains contentious. Two fundamental areas of contemporary research in moral sense development are innatism and socio-constructivism.

Innatism and socio-constructivism are the primary lines of inquiry in the field of moral sense development research. Innatism is the innate moral sense which is present from birth or inherent to our humanness. Socio-constructivism is the theory that our moral sense is influenced by and developed over time in response to our environmental culture.[49]

Our moral sense is also associated with the evolutionary process of the human species. Limone explains how some evolutionary studies have suggested that human morality derives from group selection. As we evolved as a species we encountered socio-ecological conditions which determined group selection as the dominant evolutionary

force. Through natural selection our cognitive abilities, emotions, and motivations, necessary for groups cooperation, have developed. Some will see our moral sense coming from the human need to preserve kinship for mutual survival. This can only be a small part of the answer because though we are left with our “ape morality,” which explains some areas of our innate morality, our moral sense is much deeper and more complex than this.[50]

Limone explains how an innate moral core exists in toddlers and young children, associated with the appearance of neuroplasticity and complex behaviours.[51] Before the age of one, there’s an ability to identify and evaluate others based on their prosocial or antisocial acts. One study confirming innatism uncovered four socio-moral values that guide a child’s reasoning and expectations, including justice, group support, avoidance of harm, and respect for authority.[52] Other studies show that an intuitive sense of fairness emerges within the first two years of life, modifying many aspects of one’s moral responses.[53] It was demonstrated that in children, an intuitive sense of fairness develops from their experiences and interactions. The child’s sense of fairness facilitates their ability to participate in and understand social exchanges, assuming both the role of givers and receivers of just or unjust words or behaviour. It is fascinating to note that cultural differences model when children develop a sense of fairness, with significant differences across countries.[54] Interestingly moral distress can be affected by individual values and the local culture.[55]

Though the number of studies included in Limone’s review was small it fairly highlights the complexity of the nature / nurture debate regarding the development of moral sense. However, the strict inclusion and exclusion criteria used, and the small number of articles, may have limited their ability to comprehensively reach a definitive conclusion, with more research needed in this area. Those of a religious and/or spiritual bent may agree with the author’s conclusion, though perhaps for different reasons, that though we are born with an inherent moral sense it can be nurtured both through our environment and also our social interactions.

As 12 Step spirituality is one of the primary lenses through which this research is conceptualized and advanced, how might our moral sense be viewed from a religious and/or spiritual perspective?

1.2.3. Moral Sense & Spirituality

> "And after the earthquake a fire; but the Lord was not in the fire: and after the fire a still small voice. And it was so, when Elijah heard it, that he wrapped his face in his mantle, and went out, and stood in the entering in of the cave. And, behold, there came a voice unto him, and said, What doest thou here, Elijah?"— 1 Kings xix. 12, 13.

What is that still small voice that speaks our truth to us? It is a voice that can be quietened by denial, drugs, repression, self-absorption, and a myriad of other ways, yet can never be truly silenced.[56]

Does the contemporary obsession with "the science" represent a fundamental spiritual insecurity? Though the scientific method[e] has indeed provided many technological marvels (and monsters), this modern proclivity for blind faith in "the science" is akin to the religious dogmatism and authoritarianism of the Middle Ages. This was displayed most glaringly during the COVID-19 pandemic with some scientists censored and "burnt at the stake" for daring to question policies such as mass quarantines, experimental vaccination for babies, and prolonged isolation.[57] The human mind has a deep need to understand its world and make sense of what is unfolding, when in reality, our limited sensory abilities will never let us fully comprehend what is taking place.[58] Worshipping of science as an infallible god could indicate our desperate need to believe in a predictable and measurable objective world 'out there' upon which we can depend.[59] Where science ends spirituality begins. As Pope John Paul II so eloquently states… "Science can purify religion from error and superstition; religion can purify science from idolatry and false absolutes. Each can draw the other into a wider world, a world in which both can flourish."[60] For this reason the interdisciplinary research perspective of

[e] The scientific method is an empirical and reproducible method for acquiring knowledge that has facilitated scientific progress since first popularized in the 16th Century. "The scientific method involves careful observation coupled with rigorous skepticism, to minimize cognitive assumptions that can distort the interpretation of the observation. Scientific inquiry includes creating a hypothesis through inductive reasoning, testing it through experiments and statistical analysis, and adjusting or discarding the hypothesis based on the results."[61]

this thesis, exploring moral distress through both spirituality and psychology could provide new insights.

Two common words used when we consider a person's character are moral and spiritual. We may find ourselves discussing that someone has a strong moral compass or is very spiritual. In Christianity it is believed that our sense of right and wrong is inherent, a function of the Holy Spirit that dwells within all – that we are created in the image and likeness of God.[62] In chapter 14 of John's Gospel, Jesus calls this Spirit the "Advocate" (v. 16) who is "with you and in you" (v. 17), makes us live with the same life that he lives (v. 19), and unites us to everything else (v. 18, 20) and this "spirit of truth" will "teach you everything" and "remind you of all things" (v. 26).[63] It is interesting to note that Christ says we will be reminded of the truth, not taught, thus implying truth's innate nature. This spiritual perspective of moral sense, or what may be called conscience, again sees morality as both inherent and also evolving, dependent on one's environment. If our moral sense can indeed evolve and develop, then spiritual practices and education for dealing with and healing from moral distress become relevant.

Phenomenological ethics, especially pertaining to the British moral philosophers in the 17th century, frequently referred to as sentimentalists, proposes that moral distinctions not only originate in reason but also in sentiment.[64] Newman[f] called this connection between his sense of spirituality and his morality, his conscience. He highlighted that conscience was the vital principle and sanction of religion in the mind implying a relation between the conscience and something outside oneself.[65] Newman articulated how we gain insight into religious truths over time, with this developing perspective also pertaining to morality and spirituality. In a statement reflecting his own experience regarding the development of doctrine, he lucidly… "expresses the importance of ongoing development in morality and spirituality as… to live is to change, and to be perfect is to have changed often."[65(p96)] This ability to change may prove vital to the HCP dealing with the realities of moral distress in healthcare.

[f] Blessed John Henry Cardinal Newman (1801-1890) was an Anglican vicar who converted to Catholicism. Catholicism could be fatal at that time and converting to it from the Church of England was a potential death sentence. Due to his contributions to morality and spirituality, Pope Benedict XVI beatified him in 2010.[65]

For the religious, we are born with a particular God given potential which our environment, culture, and primary caregivers can actualize. Many people have experienced the cathartic potential for suffering as a possible wakeup call to actualizing this potential for loving goodness. Thus, our morality, as evidenced by many people's experiences, can change no matter what our age or circumstances. Merton speaks with breathtaking beauty that… "at the center of our being is a point of nothingness which is untouched by sin and by illusion, a point of pure truth, a point or spark which belongs entirely to God, which is never at our disposal, from which God disposes of our lives, which is inaccessible to the fantasies of our own mind or the brutalities of our own will. This little point of nothingness and of *absolute poverty* is the pure glory of God in us."[66(p142)] However, that Spirit within us, our True Self,[g] becomes obscured by our ego and the traumas we suffer as we develop. These wounds are the painful and inevitable by-products of living in our contemporary toxic culture.[67] When we reconnect with our True Self, through great love or great suffering,[68] we can touch that intuitive morality deep within us. This reconnection can be achieved through the daily living of the 12 Steps of AA. Through practicing the 12 Steps one slowly develops the virtues for dealing with, and healing from, shame, powerlessness, guilt, non-acceptance of reality, helplessness, and hopelessness. 12 Step spirituality provides the tools to develop the virtues that the philosophy of virtue ethics articulates. What then is virtue ethics, how might it connect with 12 Step spirituality, and what can it teach us about moral distress?

1.3. Virtue Ethics & Spirituality

> "We are fired into life with a madness that comes from the gods and which would have us believe that we can have a great love, perpetuate our own seed, and contemplate the divine." Plato

There are many shared sequelae, symptoms, and concepts, such as powerlessness, shame, hopelessness, courage, and acceptance, between moral distress and recovery from alcoholism using the 12 Steps. Are there some commonalities and potentially shared modalities to be found in the healing initiated in the development of Aristotelian

[g] Thomas Merton is synonymous with the terms "true self" and "false self". The "false self" is to Merton, an illusion… "every one of us is shadowed by an illusory person: a false self… my false and private self is the one who wants to exist outside… of reality and outside of life. And such a self cannot help but be an illusion."[69(p34)]

virtues in 12 Step spirituality, and moral distress in healthcare? To answer this question let us briefly review the work of Alasdair Macintyre, the modern Aristotle of virtue ethics, and draw some connections with 12 Step spirituality.

1.3.1. Macintyre

Macintyre,[h] the modern Aristotle of virtue ethics, makes several claims in his seminal tome, *After Virtue*.[70] He posits that the moral narrative that followed the Enlightenment was doomed from the start due to its use of an incoherent form of morality. He particularly saw the Enlightenment's abandonment of Aristotelianism and the concept of teleology as fundamental to this moral confusion. The prescription of moral agency to the individual, and the individual as God, also reduced morality to merely an exchange of personal opinions. In seeking to find an alternative to Nietzsche's morality he concludes that only classical Aristotelian philosophy can save humankind.

> "It is only possible to understand the dominant moral culture of advanced modernity adequately from a standpoint external to that culture....as a result of disruptive and transformative social and moral changes in the late Middle Ages and the early modern world, moral rules and precepts had to be understood in a new way and assigned some new status, authority, and justification."[70] (pix)

Macintyre explains that in Greek, Medieval, or Renaissance cultures, where moral thinking and doing is structured according to a classical style, the primary means of moral education is the telling of stories. These stories provided an ethical setting to the issues of the day in classical societies and yielded an illuminating contrast to the present. Storytelling is also primary to 12 Step spirituality; where it is central to exploring the fundamental mysteries of who we are, why we are, and how we are to live. In one alcoholic sharing with another their failures and imperfections, a common humility and healing can occur. Maleficence is not assumed, where ignorance will suffice, as without sin our arrogance would know no bounds.[72] Historically, listening to stories and telling

[h] "Alasdair MacIntyre has contributed to the diverse fields of social, moral and political philosophy. He is one of the leading proponents of a virtue ethical approach in moral philosophy, part of a wider attempt to recover an Aristotelian conception of both morality and politics. His return to ancient sources has been powered by a critical indictment of the modern moral predicament, which MacIntyre regards as theoretically confused and practically fragmented; only a return to a tradition which synthesizes Aristotelian and Augustinian themes will restore rationality and intelligibility to contemporary moral and political life."[71]

them helped us to live humanly. For the most part the skill of storytelling and listening has been lost. As our world becomes ever faster, more fragmented and polarized, people have less time for a carefully told tale. Thus, distracted by the news and Twitter / X©, many no longer have the chance to listen to those who speak of the eternal values for living a life of meaning. What could be more important? What is the meaning of life, if not a life of meaning?

A human in Homeric society is what they do. Their actions and character are one and the same. In a 12 Step meeting room you may hear a speaker share, somewhat tongue in cheek, that their intentions were always good, unfortunately however the world judged them on their actions. It was thus so of the Homeric person. The sense of aidos or shame the heroes of the Iliad may have felt is often seen and felt in the newcomer in AA. It has been said that the society depicted by Homer knew nothing of guilt and only shame.[73] The newly sober alcoholic in AA is frequently tortured by both. We are all a product of the past and the heroic society is a part of that. The formation and conceptualization of our moral culture is shaped in no small part by the influence of Homeric society.

Macintyre explains how part of Plato's strategy to expel the Homeric influence from the polis is enabled by Plato's own articulate and well-integrated account of the virtues. For Macintyre to enquire into the virtues in classical society he turns to Sophocles in the Philoctetes, highlighting a connection between the fundamental incoherences in classical and Homeric society. Odysseus behaves according to the exact values which govern his behaviour in the Odyssey. "He does good to his friends and is harmful to his enemies, thereby fulfilling one of the definitions of justice rejected by Plato in the Republic."[70(p131)]

The appeal to, or intervention of, a god in Greek tragedy will often highlight some inconsistencies in the moral vocabulary or behaviour. For example, the intervention of Athena to resolve issues between her and Apollo establishes a new conception of justice, whereby the nexus of authority in ethical deliberations moves from the family to the city-state.[70] The concept of Homeric honour can be challenging to comprehend to the modern mind. Essentially… "it is a system of values stemming from the belief that

no harm done to self, kinsman, friend or property should remain uncompensated or unavenged."[74(p156)] The question of honour in Homer is what is due to a king, whereas in Sophocles this has shifted to what is due to the man. The competitive virtues apparent in Homeric society are contrasted against the now cooperative virtues representative of the social world of Athenian democracy. By the fifth-century BCE Greek thought has provided us with a set of words signifying virtue and thus a received set of virtues, including courage, wisdom, justice, friendship, and self-restraint. Macintyre warns us to be wary of too readily referring to 'the Greek view of the virtues.' 'Greek' may be mistakenly employed where we ought to say 'Athenian' and there were also a variety of Athenian views. However, the usual Athenian belief was that virtues could exist within the social context of the polis, though what was seen as just in democratic Athens may be viewed differently in aristocratic Thebes or in military Sparta.[70]

For Plato virtues are both necessary and in accordance with other virtues. Plato's thesis regarding the unity of virtues is reiterated both by Aristotle and by Thomas Aquinas, regardless of their other important differences. "The presupposition which all three share is that there exists a cosmic order which dictates the place of each virtue in a total harmonious scheme of human life. Truth in the moral sphere consists in the conformity of moral judgment to the order of this scheme."[70(p142)]

Macintyre sees Aristotle as representing a long tradition, and yet he argues that to treat Aristotle as part of a tradition is not a very Aristotelian thing to do. Aristotle, though acknowledging his predecessors, believed that his truth would render what came before as now irrelevant. Macintyre sees what came before as complementary and necessary, as in much of previous scientific inquiry. Einstein's theory of relativity did not negate Newtonian physics, nor make it incorrect; it gave us another deeper perspective with which to see reality. In Aristotle's *Ethics* he argues we have a specific nature with goals and needs which dictate our movement toward our purpose. He gives an account of the *good man,* universal and yet influenced by the city-state. For Aristotle the virtues are... "precisely those qualities the possession of which will enable an individual to achieve eudaimonia and the lack of which will frustrate his movement toward that telos."[70(p148)] The virtuous person does what is virtuous because it is virtuous, and the practice of the virtues requires discernment as to when to do the right thing in the right place at the

right time. In 12 Step spirituality it is simply asked that one do the next right thing, one day at a time.

A criticism of Aristotle is his dismissal of non-Greeks and slaves as being incapable of possessing political relationships. Of course, at that time this view was prevalent, and it would be unfair to judge Aristotle's worldview from our contemporary perspective. No doubt Aristotle would find modern displays of virtue signaling or moral grandstanding quite abhorrent.[i]

An overarching critique of both Aristotle and Macintyre is that they are brilliant at giving us the what and why yet become quieter on the how. Where can I find this moral courage that they speak of? Evangeliou makes the point succinctly when he states that if the reader of *After Virtue*... "had expected to find in this book concretely how a revived Aristotelian tradition is supposed to work in order to shape ethically and rationally the irrational and disorderly modern world they may be a little disappointed in their expectations."[76(p134)] In 12 Step spirituality one is given the tools to ethically and rationally shape their irrational and disorderly world.[7]

Why are the phenomena and feelings of powerlessness, shame, non-acceptance, hopelessness, fear, guilt, and helplessness, so prevalent in moral distress, also so prevalent to those who practice the 12 Steps? To answer this question we will need to look at those who practice the 12 Steps and what would drive them to 12 Step spirituality.

1.4. Alcoholism & 12 Step Spirituality

> "Above all, don't lie to yourself. The man who lies to himself and listens to his own lie comes to a point that he cannot distinguish the truth within him, or around him, and so loses all respect for himself and for others. And having no respect he ceases to love."[77] Dostoevsky

[i] "A basic contention is that one grandstands when one makes a contribution to public moral discourse that aims to convince others that one is "morally respectable." By this we mean that grandstanding is a use of moral talk that attempts to get others to make certain desired judgments about oneself, namely, that one is worthy of respect or admiration because one has some particular moral quality—for example, an impressive commitment to justice, a highly tuned moral sensibility, or unparalleled powers of empathy. To grandstand is to turn one's contribution to public discourse into a vanity project."[75]

A defining characteristic of the alcoholic pre-recovery is a progressive diminishment in their ability to see the harm they are causing to themselves and others. Irrespective of whether this is called denial, delusion, dishonesty, or lack of insight, it is so powerful it often leads the alcoholic to their death. That being said, it is widely accepted today that addiction is a biopsychosocial and spiritual illness of the human being and not a condition of poor moral character.[78] The biopsychosocial model of addiction sees these intersecting systems as fundamental properties of health and illness. Engel's original biopsychosocial model argued that the medical reductionist theories be replaced by models adhering to general systems theory.[79] This contemporary model for addiction attempts to address the complexity of addiction and recovery and is suited to the interdisciplinary researcher, as it is both applied and descriptive.

The moral status of addiction has been debated long and hard. An unhelpful binary was historically applied where either addiction was a disease of the brain or was due to poor willpower. "The former absolves responsibility and the latter condemns the person, and thus distinguishes between deontological and utilitarian positions."[78(p4)] This either / or thinking fails to take into account the fact that the brain both shapes our experience of reality and is itself shaped by our experiences.[j]

A person in active addiction, typically of somewhat good character may, through acts and words of commission or omission, do or say bad or wrong things. These acts and words of compulsion happen in a desperate need to obtain the relief of their drug or alcohol. In this respect, addiction is a moral issue. Eventually this overwhelming obsessive need for the drug in active addiction collapses in the person's choices to the point where the concept of choice becomes essentially meaningless. An analogous example would be holding someone's head under water for 30 seconds and asking them to choose not to breathe when you pull their head out of the water. No matter how much they wanted to choose not to breathe (even if told they would be harmed) the need for the relief of oxygen would win; just as the need for an addict's drug will win out in active addiction until the cycle is broken and the person enters recovery. One way

[j] Ironically this all or nothing thinking is often seen in the alcoholic pre-recovery. They will tend to see the world as a binary construct, dividing experiences into categories such as "black or white" and "right or wrong." Common phrases and words these individuals may use include, should, never, always, and cannot.

that this cycle may be broken, and a person begin healing, is to develop through a community a daily spiritual program of recovery. The most popular programs, freely available in most areas, being the various 12 Step programs of which Alcoholics Anonymous (AA) was the original.[k]

In a self-perpetuating cycle it has been shown that HCPs experience substantial distress related to morally injurious events, which in turn might increase their likelihood of nonprescription drug use, problem drinking, and the misuse of other illicit drugs, with men in healthcare particularly at risk.[81]

Two of the main phenomena described by sufferers of moral distress and moral injury are shame and guilt. Feelings all too familiar to the newly sober alcoholic.

1.4.1. Shame & Guilt

> "Two distinct ways of feeling 'bad' afflict every human being. How those afflictions work and how they can be healed, find clearest expression in the lives of alcoholics and addicts. Neither experience is unique to the alcoholic, but each has a special place in the process of recovery from alcoholism. In this area perhaps more than in any other, alcoholism and its healing contribute to our knowledge of the human condition. They do this first by revealing the importance of distinguishing between these two often-confused phenomena. Most hurting people could profit from learning this distinction, but for alcoholics and addicts, learning and living it become a matter of life and death. The distinction is between guilt and shame."[8(p4)]

It has been said that guilt is "I did something bad" and shame is "I am bad." Kurtz[l] explains how shame differs from guilt and importantly because they differ, any modalities for healing must also differ. The alcoholic and many other sufferers of guilt and shame can ill afford to ignore the distinction between these closely related

[k] AA was founded in the United States in 1935. In 1941, Rev. George Little, a non-alcoholic Toronto minister, read a newspaper review of AA's basic text, the Big Book. "He ordered a copy and was so impressed that he immediately began making copies of chapters and passing them around to those whom he thought it would help. He was such an advocate of the Big Book that A.A. Headquarters granted him Canadian distribution rights in 1942. The first A.A. meeting in Canada was held in a room above the Little Tavern in Toronto on January 13,1943 with six alcoholics in attendance."[80]

[l] Ernie Kurtz is the author of *Not-God: A History of Alcoholics Anonymous* which was his doctoral dissertation at Harvard University. He was also a Catholic priest and an alcoholic.

phenomena. For alcoholics it is vital they distinguish between guilt and shame, to facilitate the healing required for contented sobriety.

From the perspective of psychological scholarship guilt has been demarcated between altruistic guilt and deontological guilt, with altruistic guilt resulting from having caused harm to an innocent person, through omission or commission, whereas deontological guilt is caused by violating an ethical value.[82] While deontological guilt is a self-directed and inner feeling, not requiring an external agent, altruistic guilt needs an outside factor, typically another person, to be elicited.[83(p101)] In the moral distress of the HCP or active alcoholic it would seem likely that both these forms of guilt, to varying degrees and times, could be at play. It is interesting to note that feelings of deontological guilt appear to be associated with shame and sadness, whereas altruistic guilt, involving more interpersonal emotions, was associated with intense feelings of compassion and sadness.[83]

For the newly sober alcoholic who is practicing the 12 Step spirituality of AA, confronting guilt, though painful, is not difficult. The beginner in AA may find their guilt relieved somewhat by the same powerlessness and unmanageability that invites them to face their shame. In the inventory, fact finding, confession, amendment, and forgiveness Steps (Steps Four, Five, Eight, and Nine) the recovering alcoholic will find further practice and seek assistance in dealing with the resolution of their guilt. Though a beginning has been made, for the alcoholic facing one's shame, a process started by AA's first step, proves more challenging. Although chronological in order, AA's 12 Steps are synergistic in nature, and once again the whole AA program and especially Steps Two, Six, Seven, and Ten, offer a solution from the bondage of shame. AA's success in dealing with shame and guilt, and the non-acceptance of reality, flows directly from the combined synergy of the AA fellowship's peer-to-peer support and identification, and the AA program's 12 Steps effectiveness at healing shame through forgiveness and acceptance. The importance of identification and peer-to-peer support for HCPs suffering from moral distress will be addressed in Chapter Four and Chapter Five.

Rohr speaks of an incarnational worldview that grounds Christian holiness in objective and ontological reality instead of merely moral behaviour.[84] The alcoholic who can feel

as holy in a church basement or hospital bed, as in a chapel. The alcoholic having had a spiritual awakening through practicing the 12 Steps can then see Christ (higher power) in their fellow broken alcoholics as much as in normal people, whatever they may be. The alcoholic can then love and forgive themselves and others, because at our core we carry the Imago Dei equally.[84] When the alcoholic finally fully realizes that he is no better than you and no worse than you, his journey to freedom from shame truly begins.

Guilt and shame are feelings expressed by many of the participants in this research study. In the veteran population who may be suffering from moral injury, shame is one of the most crippling and difficult to treat sequela.[4,85] Sometimes the veteran's potentially morally injurious experience (PMIE), or set of experiences, may lead to the collapse of the person's entire structure of morality.[86] In this veteran population research continues to look at ways of treating and healing from the profoundly disabling effects of shame, with the concept of self-forgiveness a promising avenue of study. In fact, acceptance and forgiveness therapy is now one of the most promising modalities being studied in veterans healing from moral injury.[87,88,89,4] The association between shame and addiction has also led researchers to examine the potential for self-forgiveness as a healing modality for addiction recovery.[87]

Let us now delve deeper into 12 Step spirituality and its genesis. What might it be able to teach us about dealing with and healing from the common sequelae of moral distress such as powerlessness, shame, fear, guilt, hopelessness, non-acceptance, and helplessness.

1.5. 12 Step Spirituality

What then does spirituality mean? For many it may touch upon the Divine, Love, Truth, Kindness, and Mystery.[90] Typically, the spiritual person will seek a connection with their fellow sufferers on the road; will aim to practice kindness and compassion; will have some spiritual practices that keep or nurture their connection to their God, Higher Power, nature, or other. Yet it is more than this. To be human is to live a paradox, for we are less than the gods, more than the beasts, yet somehow the same. What then of 12 Step spirituality?

In healing through the 12 Steps from the moral suffering of addiction, spirituality is found in that liminal space between these poles where we confront our brokenness, helplessness, and woundedness.[91] This spirituality of imperfection resonates with those who see meaning in the absurd and light within the darkness, whilst accepting the necessity of suffering as a teacher.[90] Through the Desert Fathers, Saint Augustine, Saint Francis, the Reformation, Eastern mysticism, William James, and Carl Jung, this spirituality continued to challenge the narrative of perfection. To most alcoholics though these insights, practices, and this Way of hope, healing, and redemption, remained closed off.[90(p3)]

This all changed in 1934 on a chilly, rainy afternoon as two alcoholics sat at a kitchen table in Brooklyn:

> On the table was a bottle of Gin, recently retrieved from its hiding place in the bathroom, and two glasses. Ebby, neatly groomed and bright-eyed, smiled as Bill hopefully offered him a drink. Disappointed but curious, I wondered what had got into the fellow. He wasn't himself. "Come, what's all this about?'' I queried. He looked straight at me. Simply, but smilingly, he said, "I've got religion.'' My friend sat before me, and he made the pointblank declaration that God had done for him what he could not do for himself. His human will had failed. Doctors had pronounced him incurable. Society was about to lock him up. Like myself, he had admitted complete defeat. Then he had, in effect, been raised from the dead, suddenly taken from the scrap heap to a level of life better than the best he had ever known! Had this power originated in him? Obviously, it had not. My friend suggested what then seemed a novel idea. He said, "Why don't you choose your own conception of God?'' That statement hit me hard. It melted the icy intellectual mountain in whose shadow I had lived and shivered many years. I stood in the sunlight at last. It was only a matter of being willing to believe in a Power greater than myself. Nothing more was required of me to make my beginning.[5(p8-12)]

The 12 Step spirituality found in the church basements of Alcoholics Anonymous meetings is more concerned with questions than answers, more a journey toward humility than perfection. How might this differ from religion?

Spohn articulates two spiritualities, that of lived spirituality and reflective spirituality.[92] He believes it is possible to distinguish spirituality from religious dogma. He sees spirituality as focusing not on faith itself, but on the response that faith produces in religious consciousness and practice. He also distinguishes spirituality from Christian ethics as it

may not treat one's words and actions in their relation to God. It will, however, treat those acts in which the relation to God is obvious and pressing. He makes an understandable attempt to… “distinguish morality from ethics, and spirituality as lived experience, from spirituality as academic reflection.”[92(p111)] Morality is seen as the fundamental narrative flowing through our experience of human principles and obligations. Ethics is viewed as the secondary reflection that investigates their rational foundations and systematic interconnections.

Lived spirituality, which he sees as… “analogous to morality, refers to the practice of transformative, affective, practical, and holistic disciplines… and seeks to connect the person with reality's deepest meanings.”[92(p112)] In 12 Step spirituality this would be practicing the principles of the 12 Steps, especially Steps Ten, Eleven, and Twelve. The practices imbedded in these steps include continuing self-inquiry, amends and forgiveness (Step Ten), prayer and meditation (Step Eleven) and love in action (Step Twelve). These practices can be found at the core of most mature religions. In contrast, reflective spirituality (ethics) employs scriptural, historical, anthropological, and narrative methods to analyze human experience. How then does 12 Step spirituality help one to move from a nihilistic state of hopelessness to one of hope, and then eventually faith?

1.5.1. Hope, Faith, & Belief in 12 Step Spirituality

Turning to the Desert Fathers, Spohn sees their attentiveness coming out of familiarity with emptiness. Their patiently learned attitude of abandonment that comes from prolonged desert experience and attachment to God making their detachment possible. He gives an AIDS ward or shelters for the abused and addicted as examples of today's deserts. This lived spirituality is more about faith than belief. It is vital here I attempt to articulate what I mean by faith and belief. To navigate in the world amongst our fellow humans we need some belief, expectations, and opinions. These are necessary up to the point they are no longer needed to maintain our ongoing actualization. Incorrectly, we often use the words belief and faith interchangeably. However, in some ways belief and faith are opposites. Belief may be seen as the assertion that the truth is what I think it should be. I will believe so long as it fits my preconceived cultural programming and biases. Thus, faith is a complete opening of the mind to the truth, whatever it may

happen to be as… “Faith has no preconceptions; it is a plunge into the unknown. Belief clings, but faith lets go. In this sense of the word, faith is the essential virtue of science, and likewise of any religion that is not self-deception.”[93(p24)]

So, the human of faith will see all as of equal worth and dignity; will see the mystery and redemption of suffering and death. Suffering as not something to be avoided, nor asked for, yet patiently and lovingly borne when it visits. We are born dependent and will die dependent. This is the truth that no human is an island, and so long as we suffer under the delusion of separateness, we will never know peace.

The purpose then of specific 12 Step spiritual practices is to develop and deepen habits, which over time will form a personal character, which is virtuous in nature. In 12 Step spirituality these practices are the daily working of one or more of the 12 Steps, and the principles embedded within them. In 12 Step spirituality one of the most transformative aspects is the identification of one alcoholic (human) with another. In this identification of one broken human with another, a divine connection can take place: you’re no longer alone. I know your pain, shame, confusion, and fear. Here is the Way out.[5] As Spohn articulates, spiritualities require conversion and dedication to worthwhile sources of meaning, to forge an authentically transformed identity. The necessity of this identification of one HCP to another in healing from moral distress is highlighted in Chapter Four and Chapter Five.

Moral resilience involves developing the HCP’s ability to navigate moral adversity.[94] As we will see in Chapter Four resilience and meaning formed one of the four major Group Experiential Themes (GETs) of this research. Let us now look at moral resilience through the lens of 12 Step spirituality and Frankl’s philosophy of meaning, and how HCPs and their workplaces might cultivate resilience and restore their moral integrity.

1.6. Moral Resilience

> “I believe resilience is the secular word for faith — the ability to trust and let go.”[95] Richard Rohr

1.6.1. Introduction

Though the solution to moral distress is often at an organizational level, moral resilience allows the HCP to harness their inherent capabilities to restore or preserve their integrity and to engage in transforming their workplace.[96] Moral distress has previously been compared to physical pain, in that it is essentially a manifestation of a problem within the organism or organization. In fact moral distress is not a symptom of a HCP's deficiency or failure but rather a signal of their moral conscientiousness.[97] To be able to adequately respond to one's conscience HCPs need to deepen and maintain a connection to their principles and commitments in conditions that foster their integrity and resilience.[96]

Resilience is a concept that has been applied in various disciplines including business, systems, and perhaps most often in psychology. Resilience is seen as the ability to recover or adapt to life's inherent stresses, disappointments, challenges, adversity, and traumas.[98] The concept of resilience has been described as involving the formation of meaning in life, a life which has suffering and pain, and having the courage to partake in all the joy and pain despite the inherent suffering and apparent futility. From a systems perspective, resilience has been defined as.... "The ability of an entity— e.g., asset, organization, community, region—to anticipate, resist, absorb, respond to, adapt to, and recover from a disturbance."[98 (p112)] Resilience then can be seen as the ability to "bounce back" after distress - for an organism to return to a state of homeostasis. In humans though the state to which one returns may, if the distress has been processed and worked through, be at a stronger and more conscious level. This speaks to the potentially positive aspect of consciously processed suffering.[99]

For HCPs, resilience may be seen as a combination of attitudes such as living authentically, maintaining a healthy perspective, and behavioural skills, and is linked to improved health measurements.[100] At an organizational level resilience is developed by ensuring that the right resources are provided for the demands of the job. The workplace should foster a culture of honesty and transparency. These organizations will then be well positioned to achieve strategic goals and face challenges which may arise

both during emergencies, such as a pandemic, and during their regular day-to-day operations.

1.6.2. Moral Resilience and the Philosophy of Victor Frankl

Would the absence of moral distress indicate a healthy detachment from a morally challenging event or simply self-centered indifference to another's suffering? Lutzen asks can one find meaning and develop moral resilience despite being repeatedly involved in ethically complex situations, and attempts to answer these questions while drawing on the philosophy of Victor E. Frankl.[m] Analyzing two hypothetical potentially morally distressing scenarios, using Viktor Frankl's existential philosophy, Lutzen exposed a potential theoretical link between moral distress, moral sensitivity, and moral resilience.[64] In studying the relationship between moral sensitivity, moral distress, and moral resilience as connected mechanisms of moral agency, Lutzen aimed to expand our understanding of moral distress. She sees moral agency in healthcare as a fundamentally dynamic, inter-relational process that is prompted by moral sensitivity. Moral sensitivity is simply an awareness of the moral implications in making a decision on behalf of another person, typically a patient.[101] Lutzen concluded that a HCP's moral sensitivity arouses unpleasant emotions, that could be described as moral distress, in circumstances in which the HCP is unable to act on their moral agency. Through repeated experience and processing, as validated in the hypothetical scenarios, she believes that moral distress could be limited.[64] Importantly for this research this could be achieved through multidisciplinary dialogue, ethics education and role playing, and respecting the family's and patient's own wishes. Lutzen concludes that… "relational engagement enhances moral resilience by encouraging the distinctive sense that life is meaningful under all conditions."[64(p323)]

By systematically reviewing relevant literature and employing a phenomenological hermeneutic method, Marshall explored the lived experience of moral distress,

[m] Viktor Emil Frankl, an Austrian psychiatrist and Holocaust survivor founded… "Logotherapy and Existential Analysis (LTEA), an evidence-based meaning-centered approach to psychotherapy and counselling that has been successfully applied in the treatment of conditions involving existential issues."[102] "His autobiographical book *Man's Search for Meaning*, is based on his experiences in various Nazi concentration camps."[103]

particularly relative to contemporary treatment approaches and found that self-care, moral resilience, and social provision are associated with factors such as post-traumatic growth, and self-transcendence.[102] These factors are strongly correlated with Frankl's sense of meaning, and are believed to be a key factor in maintaining wellness following existential frustration and distress. Marshall's research examined the contribution of Frankl's logotherapy and existential analysis to the conceptual understanding of moral distress and its sequelae. Detailing its application they position this method into a holistic framework promoting reconnection, renewal, and health, concluding that a holistic body, mind, and spirit methodology to the treatment of moral distress is required.[102]

Is it possible to know how we would react and make sense of any given potentially morally injurious experience? Consider Colonel Paul Tibbitts, the American pilot who dropped the atomic bomb on Hiroshima. He was apparently quite unperturbed by the unfathomable death, pain, and suffering, which dropping the bomb had unleashed upon the innocent civilians of Hiroshima. In fact, in the years that followed the nuclear destruction he even took part in public reenactments of the bombing at model aircraft shows.[104] Contrast the sense of meaning and experience of Colonel Paul Tibbitts with that of Major Claude Eatherly. Major Eatherly flew the reconnaissance plane over Hiroshima immediately before the bombing and could hardly live with himself afterwards. After the war he became a vocal pacifist, donating part of his salary for a children's fund in Hiroshima, and would send letters of apology to the victims and their families. He was treated with extensive psychotherapy, yet committed petty crimes in an attempt to prove his guilt to himself and others, and crippled with shame and tortured with nightmares, he eventually attempted suicide.[104]

1.6.3. A 12 Step Spiritual View of Resilience

If resilience is the secular word for faith, that ability to let go and trust in God's plan, then those practicing 12 Step spirituality may be ahead of the game. Members of AA will often hear and pray… "let go and let God" or "let go or be dragged." In fact, faith and surrender to God's will are fundamental principles undergirding 12 Step spirituality. In Step One the members begin to accept their inability to control alcohol and their

fallibility and brokenness as an alcoholic. Through the process of practicing the 12 Steps they progress from hope, belief, trust, to eventual faith. The AA member will often place this faith in a higher power or God.[7]

Rohr writes how even Jesus emphasized faith more than love and that without a certain ability to let go, to trust, to allow, we won't get to any new place.[95] We need to become comfortable in disorder and unknowing. If we remain in our comfort zones for too long and are not resilient enough to allow a certain degree of discomfort and awkwardness, then we will never develop wisdom and compassion and will become rigid. To have faith, and to move towards liberation from the bondage of our small self, we must be forced from the safety of our cocoons, into the liminal space, through our fear, before moving into reorder.[105] Eventually our preconceived notions and belief patterns must fail until we lose faith in our small self and reach in, in despair, to a power greater than ourselves – Step One and Step Two. Then in Step Three the alcoholic makes the decision to turn their self will over to a God of their understanding.

Step Eleven is the practice of meditation and prayer. Kornfield in viewing this surrender to God's will, or in his Buddhist philosophy simply surrender to what is, offers an insightful exploration of the power of meditation and mindfulness.[106] He explains how meditation practices are practices that facilitate our ability to focus, calm, and examine our mind with increasing compassion and ease. Initially in meditation we are faced with our ever-changing stream of thoughts, perceptions, reactions, feelings. With perseverance and patience, we can become the "silent witness," able to step back from our thoughts, resentments, and conditioned reactions. As we become more grounded in the flow of life we realize our need to grasp and cling only causes suffering. Trying to hold on to this impermanence becomes like rope burn; clinging becomes a cause of pain.[106] "It is plain that a life which includes deep resentment leads only to futility and unhappiness. To the precise extent that we permit these, do we squander the hours that might have been worthwhile… for when harboring such feelings we shut ourselves off from the sunlight of the Spirit."[5(p66)]

1.6.4. Cultivating Moral Resilience

Ethical challenges which lead to moral distress may evoke a similar stress response that we see in the fight, freeze, or flight response of the combat soldier.[107] When moral distress is acute or unrelieved, the nervous system can become deregulated and one's attention may become narrowly focused, possibly resulting in misunderstanding the situation at hand.[108] In healthcare practice, when this fight response is activated, the HCP may attempt to convince those preventing them from "doing the right thing" that it is their perspective that is faulty. The morally distressed HCP may repeatedly challenge patients or their loved ones whose views disagree with the medical recommendations. If the HCP's efforts are ineffective, they may intensify resistance, avoid the situation, or passively resign themselves to the situation. All these methods may arouse a sense of helplessness and victimization, leading over time to physical, emotional, and spiritual illness.[108]

Carl Jung[n] understood that a large part of our suffering occurs unnecessarily because people will not accept the intrinsic suffering that inherently comes from being human. Jung writes that behind the patient's mental conflict there is so often concealed all the natural and necessary suffering the patient had been unwilling to bear.[109] Ironically it is this very denial, or refusal to face the necessary pain of being human, that will ultimately bring about much greater suffering over time. "Accepting things as they are does not imply agreeing with or endorsing the decisions, circumstances, or causes of the conflict or distress, or being complacent. Rather, it suggests recognizing the situation with all its complexity as it is – not how we prefer it would be or the outcome we prefer."[17(p173)] We can plan the event but not the outcome. Simple yet not easy. Perhaps this is why Scott Peck begins his classic spiritual book with the simple yet profound spiritual axiom… "Life is difficult."[110]

Few know the pain of self-created suffering more than the alcoholic, who are often unaware of the true extent of their illness until they reach bottom and face the truth.

[n] Carl Jung was instrumental in the history of Alcoholics Anonymous (AA), and he later wrote to Bill Wilson, the co-founder of AA, about his understanding of alcoholism. "Jung saw the craving for alcohol as equivalent, on a low level, of the spiritual thirst of our being for wholeness, or union with God."[111]

However, it is often darkest just before the dawn, for then the alcoholic who surrenders to their powerlessness over alcohol and drugs, and however meekly begins to practice the principles of the 12 Steps in the community of AA, will be given not only freedom from alcohol, but a design for living that truly works. The recovering alcoholic who is then practicing rigorous self-honesty and vulnerable sharing of their thoughts and feelings, Steps Four, Five, and Ten, is now able to practice a program of self-care moving from delusion or denial towards their personal truth, however painful that may be. This requires a certain amount of courage, which the new member in AA will often receive from the en*courage*ment of those walking the path with them. Over time as many members in AA begin to develop and/or deepen a relationship with what they identify as their higher power or God, they may find this courage within.

1.7. Practices for Healing & Restoring our Moral Integrity

> "To err is human – to forgive is divine." Pope[112]

It cannot be emphasized often enough to the HCP that they are typically not the problem – yet they can be the solution. However well-intentioned one's words are it may sometimes feel like not embracing the resilience culture comes with a suggestion of failure. Resilience should not be a buzzword or a sneaky concept to deny organizational inadequacies and to promote unhealthy working conditions.[113] The goal of reducing burnout and increasing resilience in HCPs has resulted in the growth of many hospital based wellness programs. Many of these interventions focus only on the individual, which can leave one with the perception that burnout and resilience can only be tackled and healed through individual HCP's efforts. Given that systemic contributors to moral distress such as workplace policies, the regulatory environment, documentation burdens, workplace culture, and unethical leadership remain primary modifiable factors, we must not lose sight of the bigger picture.[114]

1.7.1. Healing Principles for Moral Suffering

If the root cause of much psychological illness is socio-spiritual – disconnection, alienation, adverse childhood experiences, and a lack of purpose and meaning, it will obviously follow that solutions to most of contemporary mental illness will be socio-

spiritual and not pharmaceutical. This does not refer to mental illness such as schizophrenia or psychosis, which may require treatment with medication. Even here there is very little known about the etiology and pathophysiology of these major psychiatric disorders, and contemporary knowledge of disease biology is limited, with little success in finding better therapeutics.[115]

Whilst simultaneously acknowledging the need to improve our systems, what can we do as individuals and collectively to heal from moral injury and deal with moral distress? Living a principled life is one of the fundamental outcomes of practicing 12 Step spirituality. In Step Twelve it is stated that having had a spiritual awakening as the result of these steps we then practice these principles in all our affairs. What are these principles? Some of the principles associated with the 12 Steps include acceptance (Step One); hope, trust, & faith (Step Two); surrender (Step Three); rigorous self-honesty (Step Four); courage (Step Five); willingness & perseverance (Step Six); humility & kindness (Step Seven); forgiveness (Step Eight); discernment & patience (Step Nine); wisdom & integrity (Step Ten); innocence (Step Eleven); Love in action (Step Twelve).[7] It is of paramount importance that one is able to maintain fidelity to their principles in the face of moral uncertainty and organizational pressure to act or speak in a way that they morally disagree with. If unable to hold on to and follow one's principles, then they are no longer principles but meaningless preferences, to be used and discarded as needed. Following our conscience requires courage, discernment, and oftentimes having the support of other people; a moral community such as the fellowship of AA is invaluable. This speaks to the fundamental importance of peer-to-peer support for the HCP.

1.8. Summary

This chapter has presented the background to this study of moral distress in HCPs caring for patients requiring long-term ventilation. This research will predominantly be viewed through the lenses of 12 Step spirituality and virtue ethics. There are many shared symptoms, sequelae, and concepts, such as shame, powerlessness,

acceptance, helplessness, forgiveness, and hopelessness between moral distress and 12 Step recovery from alcoholism.[2,3,4,5,6,7,8]

The possible application of 12 Step spiritual principles and practices to healing from the effects of moral distress were explored. It was shown how 12 Step spirituality and virtue ethics are two sides of the same coin, as virtue ethics explains the what and why, and 12 Step spirituality provides the how.[9]

An overview of moral sense, its genesis and development were provided, both from a psychological and 12 Step spiritual perspective. For distress to be moral distress it must be interpreted through one's moral sense, our conscience. The concept of moral sense was thus reviewed to offer some understanding and background to the phenomenon of moral distress.

Furthermore it was explored how HCPs' and their workplaces might cultivate moral resilience and restore their moral integrity.

In the following chapter I have undertaken an interdisciplinary review of moral distress and the closely related phenomenon of moral injury, with the intent that I might broaden our understanding and challenge preconceived opinions, regarding the subject matter relevant to a study in moral distress. I will also expand on the ontological and epistemological conceptualization of moral distress, both in general and through a virtue ethics perspective.

Chapter 2. An Interdisciplinary Literature Review

2.1. Introduction

The previous chapter presented the background to this study of moral distress in HCPs caring for patients requiring long-term ventilation as viewed through the interdisciplinary lenses of virtue ethics and 12 Step spirituality. The purpose of this research is to explore the phenomenon of moral distress, a particular form of moral suffering, through an interdisciplinary research lens, looking at the whole multidisciplinary team caring for patients requiring long-term ventilatory support. There are many shared symptoms, sequelae, and concepts, such as shame, powerlessness, acceptance, helplessness, forgiveness, and hopelessness between moral distress and recovery through 12 Step spirituality. Some common threads were elucidated between moral distress in healthcare and the possible use of 12 Step spiritual principles and practices for healing, and what the moral in moral distress may refer to.

This chapter will undertake an interdisciplinary review of the literature on moral distress and the closely related phenomenon of moral injury. The work of Georgina Morley and Carolina Caram,[o] foremost researchers in the study of moral distress will be significantly reviewed. The intent is to broaden our understanding and challenge preconceived opinions, regarding the subject matter relevant to a study in moral distress. This chapter will also expand upon what the literature has to say regarding the ontological and epistemological conceptualization of moral distress, both generally and through a virtue ethics perspective, and discuss the closely related phenomenon of moral injury.

2.1.1. Why This Topic?

While many researchers have studied various ethical issues that arise in long-term care, prior to COVID-19 few studies had explored the experience of moral distress on HCPs working in long-term care.[116] Furthermore, the literature on moral distress in HCPs

[o] Carolina S. Caram is a researcher who has studied moral distress in healthcare professionals, including nurses. Her work has highlighted the role of systems, cultures, and processes in contributing to moral distress.

working on long term ventilation units is severely lacking, with no research specifically exploring their experience identified. In fact, only one research paper, peripherally looking at this population and environment was identified during the literature review and ongoing research.[117]

The concept of moral distress, its causes, and the facilitators and barriers to a positive work environment, remain a work in progress. Though we have no agreed upon consensus the literature concurs on many aspects of what qualifies as moral distress.[25] At its most fundamental moral distress is the suffering one experiences when taking a path one knows or believes to be wrong. It is more than simply a set of thoughts or feelings; it strikes a wound to the core of our beingness.[118] Most human beings cannot do what they believe is wrong without suffering the consequences. Our moral sensitivity, that awareness of the moral implication in making a decision on behalf of another human being cannot be ignored.[101] In the Eastern spiritual traditions this may be known as Karma and in the Christian tradition as you sow, so shall you reap. As Christ says, “A good tree will bear good fruit and a bad tree will bear bad fruit” (Matthew 7:17-18) and “If you show mercy, mercy will be shown to you” (Matthew 5:7, Luke 6:37) and “The standard you use will be used for you.” (Mark 4:24) What Christ was saying in essence is that we are punished by our sins, and not because of our sins.

HCPs cannot escape the field of moral difficulties and suffering; it is quite literally part of the job. We know however that how the HCP is impacted both by their work environment and their own ability to discern and process moral challenges, has negative impacts on a personal, hospital, and community level. When we are clearer on what the problem is our solutions will be more effective and simpler to implement. What then does the literature say moral distress is?

2.2. An Interdisciplinary Perspective of Moral Distress

2.2.1. Distress? What Distress?

It is vital we do not confuse moral distress with psychological or emotional distress as the modalities for healing from and dealing with moral distress and emotional distress will not be the same. Moral distress may produce psychological and/or emotional

feelings and thoughts. However, the primary causative factor, *a necessary and sufficient condition,*[25] is a disturbance with the equilibrium of our internal moral compass, or if you will, our conscience.

It is important to again note that moral distress, in and of itself, is not a “bad” thing. On the contrary, moral distress can be a proper reaction to a “distressing” event or process involving moral reasoning. In this respect moral distress performs, like physical pain, a necessary though uncomfortable function – a warning sign. Morley recognizes that moral distress has… “value in its function as a warning sign, signaling the presence of an ethical issue related to patient care that requires deeper exploration, rather than evidencing identification of the "right" course of action.”[119(p980)] Though Morley sees this distress as psychological, part of our humanness, might it go deeper than this, to our very beingness as human beings?[25] Thus, an interpretative, phenomenological, interdisciplinary research approach, exploring moral distress through the lenses of 12 Step spirituality, psychology, and virtue ethics, could reveal a new and deeper understanding, which will be necessary in order to develop strategies that will help HCPs and our organizations build resilience, coping strategies, and healing modalities.

While the jury remains out on an exact definition of moral distress, some consensus sees moral distress as deriving from workplaces’ illegitimate constraints on an individual’s moral agency.[120] A broad contemporary definition would see moral distress as the… “experience of being compromised as a moral agent in practicing in accordance with accepted professional and personal values, and standards. It is a relational experience shaped by multiple contexts, including the socio-political and cultural context of the workplace environment.”[39(p59)] Moral distress is… “the suffering one experiences when they feel morally responsible and have determined the ethically right action to take, yet due to constraints (real or perceived) they are unable to conduct this action.”[121(p101)] What does this mean? What does it feel and look like?

Each separate discipline looking in at the issue of moral distress and its consequences, will have their own assumptions, concepts, beliefs, and viewpoints - their own lens. Thus, their solutions will be born from the problem as they see it, not as it is. Perspective taking involves analyzing the problem from the viewpoint of each

concerned discipline and then finding their commonalities and differences.[122] Perspective taking also involves holistic thinking.[123] Holistic thinking is the ability to understand how ideas and data from relevant disciplines speak to each other and the issue.[124] The interdisciplinarian will "create" from this holistic space and common ground. Common ground is that which is created by reinterpreting and synthesizing the various elements, formed from the disciplines, which may be in conflict.

Moral distress has now been shown amongst many HCPs, including physicians, respiratory therapists, pharmacists, psychologists, social workers, nutritionists, and chaplains.[13] Though there appears to be differences between professions in what causes moral distress and in how it presents, it is vital that this is understood to be a multidisciplinary problem. For potential solutions to this complex multidisciplinary provider problem to be effective, an interdisciplinary research approach will prove beneficial.

2.2.2. Moral Distress Development Through Virtue Ethics

Virtue ethics is an approach that presents an account of virtues. These desirable virtues, or traits of our human character, would typically be seen as necessary for one to practice as an HCP at an optimal level. These virtues also make it possible for HCPs to attain the necessary tools that are inherent in healthcare practice.[125]

Ultimately then can moral competence be developed through the acquisition of virtues? Caram proposes a new perspective attempting to understand moral distress more fully using the lens of virtue ethics… "Virtue ethics is focused on the moral character of agents as opposed to the acts, circumstances, and consequences of moral events. Virtue ethics addresses some important questions that deontological codes, restricted to regulations, neglect."[126(p1)] She further explicates the concept of moral distress in nurses using MacIntyrean virtue ethics and considers the experience of moral distress in the context of a practice. Specifically, she articulates how… "identity, social context, beliefs, and tradition shape moral discomfort, uncertainty, and sensitivity, and how virtues inform moral judgments."[126(p402)] Practicing HCPs each have a unique story and telos which guide them in their day-to-day moral judgements and if this moral competence is blocked, it may lead to moral distress.

In acknowledging that healthcare work is complex and ethically challenging, Caram presents the case that if the formation of moral competence is blocked, it may lead to moral distress and de-professionalization. This can culminate in experiences of moral distress, leading from issues such as futile care, utilizing limited resources, moral conflict with the treatment team, and the inability to be a fully participative agent in the ethical decision-making process.

Ramos, as cited in Caram, defines moral distress… "as the reaction to a situation in which healthcare professionals, when faced with a moral problem, make their judgment, but are rendered unable to act in accordance with their values and judgments."[127(p403)] Caram makes no mention of professional or organizational standards in her definition of moral distress, and specifically only references personal values. Some contemporary experts in the field of moral distress, such as Epstein, have argued that it is predominantly professional, and not personal, values that are relevant to the understanding of moral distress in healthcare.[13]

Using an ethical theory, Caram attempts to bridge the moral distress practice gap. Her goal is not the development of a new framework for moral distress development, but rather the utilization of some theoretical elements intrinsic to virtue ethics to increase our comprehension of the complexities of moral distress. She argues that ultimately moral competence can be developed through the acquisition of virtues. However, though the acquisition of virtues is helpful for the development of a morally competent human being, moral competence is only part of the solution to the causes of moral distress, causes which are often institutional and intractable to solution at the individual level, no matter how morally competent one may be.

Caram sees virtue ethics as being focused on the moral character of HCPs as opposed to the acts, circumstances, and consequences of these workers. Virtue ethics addresses some important questions that nursing or medical professional codes, or hospital policies, may neglect. These codes may limit words or actions by considering them to be permissible, obligatory, appropriate, or inappropriate. Thus, an action could have different possibilities, if the nurse or physician invokes virtues that lead them to act morally in their nursing or medical practice. This would make sense from the Buddhist

perspective, where the answer to the question what would you do if x happened in y situation, is typically answered with “I don’t know”. For MacIntyre practice is a reasoned and complex form of socially recognized human cooperation, which allows goods appropriate to that form of activity to be realized.[70]

Caram proposes that the HCP’s purpose (telos) is associated with the history and tradition of the practice and though autonomy allows some variety to how they practice, professionals will have no control over the overall purpose of their practice. They also have the ability to assign purpose to their actions, however mundane or seemingly hopeless, irrespective of whether these actions occur in a professional setting or otherwise.[103] Ultimately however total autonomy does not exist; as Donne so hauntingly wrote… “no man is an island, entire of itself.”[p]

Caram acknowledges that the processes required to achieve the practice are often time and context dependent and can vary with the moral conscience of individuals. In contrast, external goods such as money, prestige, or power can be achieved in any practice though they do not legitimize or give significance to the practice. What would corrupt the practice is the HCP prioritizing the external good over the internal good.

Virtue ethics recognizes the moral ambiguity that day-to-day clinical encounters may present and the responsibility that the HCP needs to take on when facing these ambiguous situations. In pursuing the telos of their practice, professionals must mobilize their virtues. An HCP’s life story will significantly impact their motivation to practice in harmony with their virtues and this ongoing process of socialization will influence their development as moral agents and affect whether they stay quiet or speak out when faced with morally challenging situations. The HCP’s life story is required for one to understand moral discomfort, uncertainty, and sensitivity since they arise from relationship and social interactions, with decisions not merely focused on individuals,

[p] John Donne (1572 - 1631) was an English writer and poet. “As a Catholic in a time when that denomination was illegal in England, he endured constant prejudice and harassment and was ultimately forced into joining the Anglican church by King James I. This famous quote is from his Devotions Upon Emergent Occasions, Meditation XVII. It was originally prose, not poetry, and part of a much longer piece.”[128] Its final line is perhaps the most haunting in English literature… “and therefore never send to know for whom the bell tolls; it tolls for thee.”

but part of the whole.[126] The HCP's story… "confers intelligibility to a practice, since the actions come to be situated and understood as a whole."[126(p407)]

When we see that each professional group, be it nursing, medicine, allied health, or spiritual care, pursues its own internal good, it becomes clear that conflicts may emerge due to the specificities of their roles and responsibilities. This legitimizes the rationale for conducting interviews with the multidisciplinary team and not only one specific discipline, such as nursing. In exploring the lived experience of the whole multidisciplinary team, the intent is to compare and contrast human experience as seen through the lens of a particular discipline. Will a physician experience moral distress differently to a nurse and how will a similar experience elicit moral distress in different disciplines?

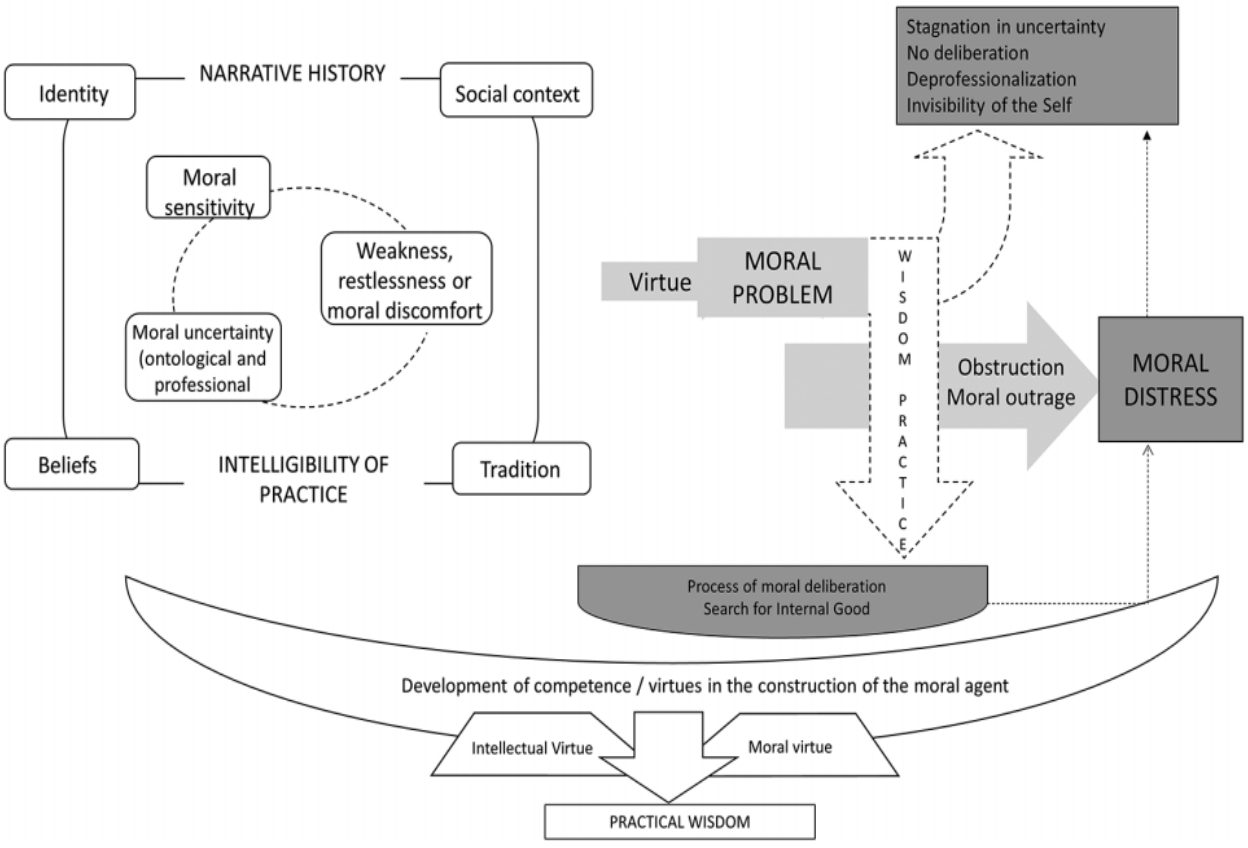


Figure 2. The Process of Moral Distress: An Adaptation of Ramos et al.'s Moral Distress Framework Using Virtue Ethics[99]

Caram builds upon Ramos' moral distress framework, moving past the singular focus on the process of moral distress itself, to investigate in-depth the process of moral distress in the context of a practice.[126] She argues that from a virtue ethics perspective, moral reasoning occurs when a virtuous HCP makes choices to realize the internal good of their health care practice. She sees the moral experience beginning with the presence of a moral problem, requiring the HCP to be morally sensitive. Thus for Caram, moral sensitivity, moral uncertainty, and moral discomfort are the required conditions to recognize a moral problem. "The context in which nursing practice develops is defined by traditions that include institutional, social, and historical influences."[126(p407)] Nurses will, by engaging in a particular practice, receive that tradition, begin to comprehend it, and add to it. The same will be true for other HCPs.

Caram shows that moral distress could be minimized if HCPs were able to engage in practical wisdom, or phronesis, as understood by Aristotle, and engage in ethical deliberation to achieve needed outcomes based on their assessment.[129] An issue in healthcare is that actions are often blocked due to institutional or other constraints. I may *know* the right thing to do, at the right place, and at the time, yet be unable to *do* it. This is the seemingly impassable bridge between knowing and doing. Consequently, a paralysis can occur when the HCP is unable to internalize their moral values, leading to an automatic and unthinking provision of health care. Pellegrino sees this position as characterized by de-professionalization.[130] Here the HCP loses their commitment to the virtues necessary for the well-being and interests of their patients. When the HCP's integrity is imperiled how might they respond?

2.2.3. Responses to Imperiled Integrity

Caram shows how for Macintyre it is possible to explore moral competence development using virtue ethics. He sees virtues as habits that can be developed and learned.[70] This includes both intellectual and moral virtues. Aristotle's point of view would see an intellectual virtue being the result of the acquisition of wisdom, while moral virtue might imply the application of virtue, e.g., courage, fairness, and freedom.

Thus, we must move past looking at moral distress as only a negative state to be avoided. Suffering is the necessary catalytic lubricant for spiritual and psychological

growth. This moral distress which imperils our integrity is often a necessary warning sign, like physical pain, that something is wrong within the system or individual. However, moral distress extends beyond its effect on the lives of individual HCPs, it further affects their systems, organizations, and communities they live and work in. Rushton **(Figure 3)** proposes a continuum of responses to imperiled integrity which reflects differences in intensity, sources, and consequences.[17] Starting with moral adversity the continuum expands to include moral stress, moral distress, moral injury, and moral decline. Though these conceptual differences could be important to the researcher, to the HCP on the frontlines in a long-term ventilation unit, they will likely do little to alleviate the emotional and moral distress they experience during a shift. Caram states that it is necessary for us to focus on the promotion of moral sensitivity and moral integrity. This can be achieved through discussion and reflection on our practice and workplace organizations, as well as on the education of HCPs in moral discernment.[131]

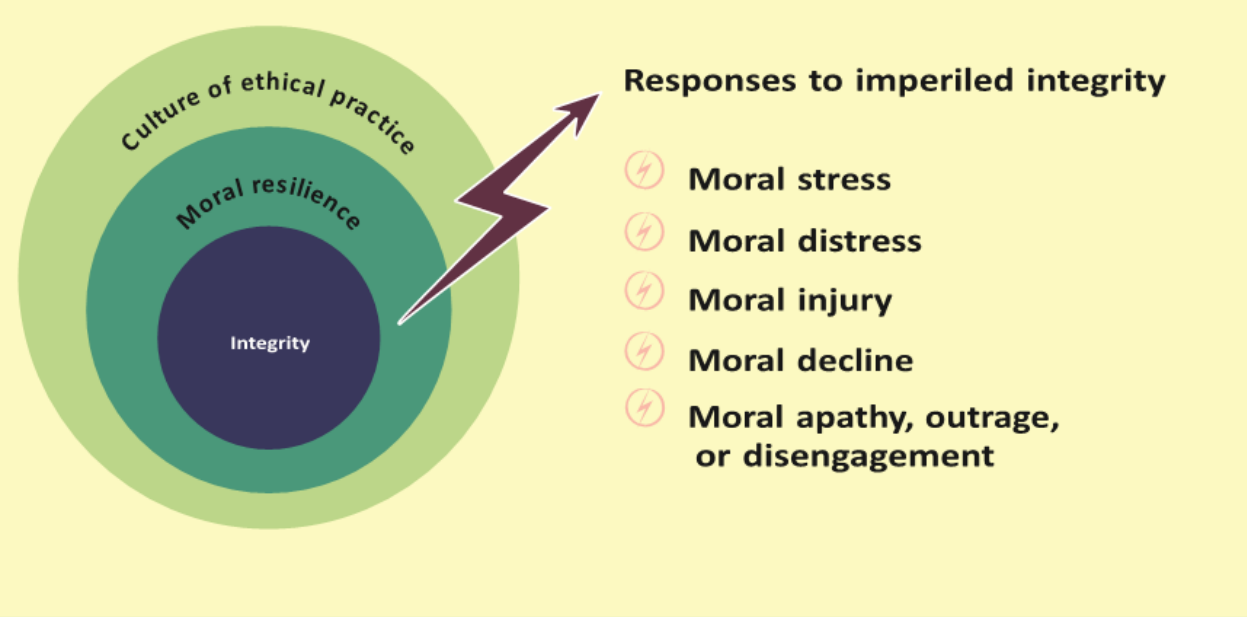


Figure 3. Responses to Imperiled Integrity[96]

2.2.4. Moral Distress and Virtue Ethics in Nursing

In their earlier work Caram examined virtue ethics as a theoretical lens with nursing being considered as the practice.[132] It was an attempt to bridge this gap in the literature by illustrating the causes and consequences of moral distress in nursing practice. It was

argued that nursing is a practice because… “notions of the good are central to the inseparability of clinical and ethical reasoning in nursing with the notion of telos, or final goal, of a practice, in the sense that each practice has its own nature… and if nursing is truly a practice, it will thus have its own telos, which differs from other practices.”[132(p2)] Caram highlights that when we are unable to reach a resolution to our moral problems and cannot express our virtues, then anguish, anger, frustration, and impotence can be generated. This suggests moral distress development is directly related to the HCP’s inability to express their virtues.[132]

In this previous research Caram found that the nurses who typically saw themselves as being incapable of fully expressing nursing virtues in their daily practice, would suffer moral distress. She concluded that when faced with conflicts in their work nurses become invisible to themselves, a phenomenon she called the invisibility of the self. “This invisibility distances nurses from their professional practice, leading them to not recognize themselves and removing them from the reach of the excellence of their practice, that is, their telos.”[132(p2)]

It is self-evident that these virtues as human characteristics, or traits, are desirable to have in nursing practice. The full expression of these virtues will allow nurses to actualize the goods inherent in their practice. Using Macintyre’s definition of a practice as …. “any coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realized,”[70(p187)] then nursing practice does have its own telos and own nature.

Exploring and understanding these differing multidisciplinary teloi is critical when undertaking research on moral distress. Will physicians, nurses, social workers, and other allied health workers, experience moral distress in unique ways? We know moral distress is experienced by all members of the multidisciplinary care team, including physicians, nurses, social workers, respiratory therapists, and spiritual care. What though are the differing purposes of each health care discipline? For example, nursing could typically be seen as the promotion of the well-being of the patient by providing good nursing care. The elements of good nursing care might need to include respectful interprofessional relationships, caring behaviour, the integration of virtue and expert

activity, and virtuous care encompassing the physical, relational, social, psychological, moral, and spiritual.[133]

Pellegrino would see the telos of medicine as ultimately to do good and avoid evil.[134] In reaching this conclusion he states that the roots of the present confusion about the ends of medicine and the need to redefine them lies in the dissolution of the classical conception of ends. For Pellegrino regaining this orthodox conception will lead to the outcome that the telos of clinical medicine is the good of the patient. His teleological approach may prove helpful when one attempts to define the ends of other health care professions, such as Social Work.

In their daily work on, for example, a long-term ventilation unit, nurses might contend with many interpersonal and institutional constraints preventing them from expressing their virtues and giving rise to moral distress. Caram surmises that when nurses are unable to resolve these moral problems and cannot express their virtues, then anguish, anger, frustration, and impotence may be generated. Put simply, moral distress arises when nurses are prevented from expressing their virtues. Examined through the lens of virtue ethics, nurses are then incapable of enacting their telos and providing the care they want to. Also, if nurses feel impeded from performing morally good acts and prevented from achieving excellence in practice, this will have consequences in the way they perceive themselves and their purpose. Importantly, domains of nursing that do not involve direct patient care, e.g., education and research, also have a moral significance, as they too are based on the moral requirement of promoting the well-being of the patient.[125(p495)]

Analyzing how nurses, as defined by themselves, attempt to attain the purpose of their work,[132] highlights the -

A. **Invisibility of self: loss of nursing identity** - This was seen as the gap between the expectations that arise during nursing education about being a good nurse and the reality of daily practice. This led to nurses not recognizing themselves in their nursing practice.

B. **Ambiguity of telos –** The reality of nursing practice is that it is filled with ethical dilemmas and moral challenges. Common causes of these challenges are an inability to provide good care due to lack of staff and an excessive number of patients. The nurses were thus unable to provide the good nursing care they wanted to provide.

C. **The domination of institutional values** - Conflict between institutional values and nursing virtues was common. Nurses saw that their values were incompatible with those of the organization.

The challenge then is to recognize the non-clinical and administrative work that is focused toward the good of patients and what is directed toward the goals of the institution. This is not always clear and there is typically no obvious binary demarcation where one ends, and one begins. Nursing, including both management and direct patient care, is subject to the competing pressures of professional and organizational needs. In the final analysis what is needed is an ability to discern what is serving the well-being of our patients and what is not. The institution must have a culture of honesty and transparency, in which moral courage is not only allowed, but is supported and *encouraged.*[26]

2.2.5. Moral Constraint Distress

Contemporary literature continues to refine and broaden the concept of moral distress, and with the intent of developing more effective and focused treatments, researchers have expanded on more specific areas relative to moral distress. A developing and contentious subcategory of moral distress in this new taxonomy has been labeled "moral-constraint distress."[135] Moral-constraint distress and the measurement of moral distress has been the focus of recent, and for the ethics literature somewhat heated, scholarly debates.[136,137,138,139,140,141] Researchers have debated the accuracy and relevance of moral distress measurement tools and have attempted to differentiate between illegitimate and legitimate constraints on HCPs' moral agency. Kolbe for example has argued strongly that for an effective reduction of moral distress, the instruments measuring it should provide relevant information about these constraints, and justified or unjustified moral distress.[120] Kolbe critiques these instruments, such as

the Moral Distress Scale (MDS) and the Measure of Moral Distress - Healthcare Professionals (MMD-HP), as failing to do so.[142,143] For example, it is implied that in some clinical circumstances an HCP's words, actions, or lack thereof, could be deemed wrong given the competing healthcare values of patients, their loved ones, and the treatment team.

2.3. Epistemology of Moral Distress

Continuing to develop a systematic and defendable definition of what one means and understands moral distress to be is necessary, whilst acknowledging that this will forever be an iterative process of insightful redefining.

Since Jameton's seminal definition in 1984 that moral distress is said to occur when one has made a moral judgement but is unable to act upon it,[24] there have been multiple attempts to redefine the concept in the literature. Morley, with good cause, writes that because of the lack of an agreed upon definition and poor conceptual clarity, the study of the phenomenon of moral distress has suffered.[25] Once again this speaks to the vital importance that the researcher and their audience are both talking and reading about the same thing. This is not to say that one's definition of moral distress must be rigid and static; on the contrary, it must be malleable to the new evidence and insights from qualitative research studies. Epstein has argued for the necessity of a narrow definition and how this has been foundational for the development of reliable, validated instruments such as the MMD-HP and for effective moral distress consultation.[141] However, there must be some common ground that most researchers in the field of moral distress can agree upon. This will be a necessary requirement to produce relevant and reproducible research relating to moral distress and its sequelae.

Morley's synthesis and analysis of 34 research papers revealed different proposed conditions for the manifestation of moral distress including… "moral judgement, psychological and physical effects, moral dilemmas, moral uncertainty, external and internal constraints, and threats to moral integrity," and from this she postulated that... "the combination of (1) the experience of a moral event, (2) the experience of 'psychological distress' and (3) a direct causal relation between (1) and (2) together are necessary and sufficient conditions for moral distress."[25] (p660)

Morley uses a term often used in philosophy, *necessary and sufficient conditions,* to define and explain the connections between the concepts and causes of moral distress. To illustrate this term, we could use the medical example of Streptococcus pneumonia. Shortness of breath and fever are symptoms associated with a diagnosis of pneumonia. They are not, however, necessary and sufficient conditions for a diagnosis of pneumonia. In this example there is one condition that is both necessary and sufficient for pneumonia, and that is the presence of Streptococcus in the lung. Morley makes the vital point that one of the main challenges we have faced in defining moral distress is that it has usually been conceptualized in terms of the conditions in which it arises, e.g., moral distress occurs when conditions A and B are met. Thus, in Jameton's initial definition moral distress will occur when (A) a moral judgement has been made and (B) there are institutional constraints preventing the moral judgement from being acted on. Though Jameton has subsequently expanded on his original definition,[28] the presence of "constrained moral judgement" was both a necessary and sufficient condition of moral distress in his original definition. Literature since has either accepted his definition of moral distress as requiring a constrained moral judgement or argued against this single condition as being necessary or sufficient.

Morley's methodological rigour is apparent in her systematic review. The approach allowed the capture of varied conceptual developments of moral distress without being too reductive. Using an evidence informed seven-step systematic review process that was mindful of the challenges when exploring a bioethical concept like moral distress, and combining it with 'narrative synthesis', she was able to perform a systematic literature search and synthesize key findings. This method was also ideally suited for drawing from multiple studies with varied methodologies and hypotheses. It was appropriate for the interdisciplinary researcher as Morley's review question and search are not limited to one specific discipline. Many studies have shown the deleterious effects of moral distress on all members of the multidisciplinary care team, including physicians, nurses, social workers, respiratory therapists, and spiritual care. These effects may include burn-out, physical & mental illness, and intention to leave the workplace or profession.[144]

Jameton's original definition differentiates moral distress from moral uncertainty or moral dilemmas and held that moral judgement and constraint were necessary and sufficient conditions for moral distress.[24] In his original work the nurses he encountered had described situations they viewed as dilemmas, in which they had made a moral judgement but were unable to act upon it. It was this inability to act that had caused the moral distress. In the years following Jameton's original research the focus remained on the difficulties of HCPs negotiating moral judgements in the presence of constraints. Morley clearly illustrates the ambiguity about what a moral judgement is. This has led to various ambiguous terms in the literature including moral judgement, moral decision, moral belief, or an awareness.

Fourie critiques Jameton's original definition of moral distress as being too narrow and rigid.[145] Might moral distress occur, though perhaps not as often, when the HCP is not certain of the next right thing, in situations seen as a moral dilemma or moral uncertainty? On this basis then many of the subsequent definitions in literature could be seen as too narrow.

Examining constraints on an HCP's ability to act led researchers to explore the relationship between an organization's ethical climate and these constraints. For some authors the violation of the HCP's moral agency, rather than constraint on action, is the necessary and sufficient condition for moral distress.[146] The violation may be caused by a constraint on action, however it is not the only possible cause. With this being the case, qualitative studies, rather than quantitative methods such as questionnaires, could be better suited to gathering the varied and rich data necessary to explore these violations of an HCP's moral identity or agency.

Epstein highlights the fact that moral distress may come not only from external constraints but also internal.[147] It is these internal constraints, such as shame, timidity, self-doubt, lack of moral courage, socialization to follow orders, and perceived helplessness that are particularly relevant to this research. These internal constraints have received very little attention within quantitative or qualitative literature. This is perhaps due to moral distress being mostly conceptualized as flowing from external constraint. These internal constraints are amenable to education and support at the

personal level. We must be very careful though that the HCP does not hear the message that they are the problem.[113] The problem directly causing moral distress typically resides outside the individual. Thus, the HCP is typically not the problem, and they have the potential to be part of the solution.

It is clear then that unambiguous language is vital and necessary when trying to understand the concept of moral distress. Morley argues that in the context of moral philosophy, labelling something as a judgement or opinion might radically alter the conditions needed for moral distress. For quantitative questionnaires measuring moral distress, which are predicated on the researcher and participant having the same understanding of 'moral judgement,' the risk of misunderstanding and conceptual conflation is apparent.[141] Thus, psycho-spiritual distress is a necessary condition of moral distress, yet not a sufficient one. One may feel distressed and upset in many healthcare situations, but it is not always linked to a moral event. Morley's use of the term psychological distress quickly reaches an ontological dead-end. Moral distress may also be seen as a form of spiritual suffering which can result in psychological sequelae and… "while it may not be possible to do so, the failure to distinguish between psychological and moral distress runs the risk of conflating the two so that all psychological distress is labeled moral distress."[26(p30)] Finally, it cannot be emphasized strongly enough that moral distress is legitimate even if it arises from accepted systemic conventions.[141(p66)]

It's apparent then that this debate is far from settled. For now, Jameton's seminal definition and Morley's contemporary definition are two true and relevant extremes on the moral distress conceptual continuum.

What now of moral injury in healthcare, and how might if differ in presentation and potential treatment?

2.3.1. How Does Moral Injury Differ From Moral Distress?

It will be vital for the development of effective healing and coping modalities that we clearly as possible differentiate moral distress and moral injury in healthcare. Though both moral injury and moral distress are forms of moral suffering and fall on the same

spectrum, they are in fact distinct entities.[148] As such the practices employed for healing from a moral injury will also require an individualized and tailored approach.[4] A moral injury is just that - an injury to one's soul or psyche. It is a moral trauma which will leave the sufferer wounded and it is this wound or trauma which must then be acknowledged, felt, and healed from.[149] Litz, one of the foremost researchers and clinicians treating morally injured military personnel, defines these potentially morally injurious events (PMIEs) as… "perpetrating, failing to prevent, or bearing witness to acts that transgress deeply held moral beliefs and expectations."[150(p700)] These moral injuries may leave long-lasting emotional, psychological, behavioural, and spiritual traumatic sequelae.[11]

For example, a nurse working in a short staffed, overcrowded emergency room, facing patients in pain and angry patient relatives, and burdened with a mountain of documentation, will likely feel some degree of moral distress as they perform their duties. This moral distress will be felt to varying degrees and frequency throughout their shift. If the environment improves or the nurse leaves, then the distress will likely dissipate without any further treatment. If the situation worsens, is prolonged and repetitive, then the continuous build-up of moral distress could eventually crescendo and leave the nurse with a moral injury.[147] At this point simply being removed from the environment will not be enough to process and heal the moral trauma. Now, let us say that a medical resident works in a well-staffed and well-run emergency room that is seldom overcrowded. The physician enjoys her work and is respected by her colleagues. She is treating a ventilated patient suffering multi-organ failure and septic shock. Due to the patient's age, comorbidities, futility, and repeated admissions, the family and consultant agree that withdrawal of treatment is in the patient's best interests. The family requests that the patient's internal defibrillator (ICD) and its back-up pacemaker be deactivated. As the resident is the only staff member experienced with the ICD, she programs the defibrillator off and turns off its back-up pacemaker. However, although the patient was not previously pacemaker dependent, the patient's heart was so sick and near the end of life that turning off the back-up pacemaker resulted in immediate cessation of heart rhythm and the patient passing on very shortly afterwards. This all happened so quickly that the family were not present. The resident, who knew intellectually that further treatment of the patient was futile, and that the patient had died from multi-organ failure, was crippled with the shame and fear of

knowing the family were not present as the patient died. Due to the temporal proximity of disabling the ICD and the patient's death she felt that she "had killed her patient and the family missed out on being present as the patient passed on." This left a deep wound, a true moral injury that would require specific healing modalities to free her from the burden of shame and soul sickness.

2.4. Summary

In this chapter an interdisciplinary and contemporary review of our understanding of moral distress and moral injury in healthcare was undertaken.

Though a clear consensus is not available regarding the meaning of moral distress and the phenomenon remains very much a work in progress, some shared conceptions were elicited. Though we have no agreed upon consensus the literature agrees on many aspects of what qualifies as moral distress.[25] At its most fundamental moral distress is the suffering one experiences when taking a path one knows or believes to be wrong.

The ontological and epistemological conceptualization of moral distress was expanded upon, both in general and through a virtue ethics perspective, and the closely related phenomenon of moral injury was reviewed.

In the following chapter the methodology, research design, population, sample, data collection methods, and data analysis procedures used within this study will be outlined and validated. Furthermore, an evidence informed rationale for the particular research methodology appropriate for an interdisciplinary study of HCPs working on a long-term ventilation unit is provided.

Chapter 3. Research Methodology

3.1. Introduction

In the previous chapter an interdisciplinary and contemporary review of our understanding of moral distress was outlined. The ontological and epistemological conceptualization of moral distress and moral injury in general, and through a virtue ethics perspective, were discussed.

This chapter will outline and validate the methodology, research design, population, sample, data collection methods, and data analysis procedures of the study. As its primary focus this study utilized an interpretative phenomenological analysis in order to facilitate a fulsome and comprehensive understanding and interpretation of the experience of HCPs caring for patients on long-term ventilation. The participants were chosen and asked to participate in the study based on a selection criterion that created a homogenous sample of HCPs working on a long-term ventilation unit. Semi-structured interviews and the Measure of Moral Distress - Healthcare Providers (MMD-HP) validated moral distress questionnaire were employed as data collection sources to capture the lived experience of the HCPs as it related to moral distress on a long-term ventilation unit.

3.2. Literature Review

A systematic literature review was undertaken to examine previous research available in journals, books, websites, and grey literature, to understand how the issues have been viewed and discussed by other researchers. Repko & Szostak provide a detailed summary explaining nine reasons why the interdisciplinary researcher ought to conduct a systematic literature search.[122] They highlight the benefits including expediency; becoming aware of what researchers and academics in other disciplines have discovered on the topic; narrowing the topic and refining the focus of the research question; explaining how the issues have developed over time; identifying previous disciplinary research and developing how an interdisciplinary perspective may extend our familiarity with the issues; to provide context to the problem; to develop a working

ability and adequacy in the relevant disciplines; and to verify that the disciplines one has identified are truly relevant and workable.

Having clearly articulated and formulated one's research problem the next step of the literature review process was collecting the data. A systematic search of Medline, CINAHL, APA PsycInfo, & AMED databases were conducted. Search terms included moral distress; long term (vent*); chronic vent*; health care personnel (nurses, physicians, health care workers). Abstracts were reviewed for relevance. References of relevant papers were also reviewed. Sciwheel© Reference Management software will be used for storing and managing the references.

3.3. Rationale for the Choice of Data Analysis in this Study

3.3.1. Introduction

Qualitative data analysis in a doctoral research project requires the researcher to choose a recognized data analysis methodology. This process will allow the researcher to advance two key points to the academy through an audit trail of the processes deployed during data analysis.[151] First, that the work was actually performed, and secondly that it was done in a systematic and evidence informed manner. Pragmatically, considering time, resources, and abilities, the researcher must create the best study design possible through considered planning.[152] Corresponding with the research aims and objectives, data analysis for this study was undertaken by conducting a review of several recognized data analysis methodologies to inform the appropriate method.

3.3.2. Grounded Theory

Grounded theory systematically analyzes data in an attempt to unearth new theoretical knowledge.[153] Grounded theory necessitates that the analysis be focused towards theory development in a "bottom up" approach.[154] It was later expanded upon by other authors to three paradigms, Classic, Straussian,[155] and constructivist grounded theory.[156] However, as to what actually constitutes grounded theory there remains some contention between researchers, with some critics arguing that it would be impossible for one to be able to extricate themselves of their preconceptions when collecting and analyzing their data, as required by the methodology of Glaser and Strauss.[157]

Grounded theory requires the researcher, following the initial data analysis, to conduct further interviews to address questions which may have arisen. This is a process known as data saturation.[158] The constructivist grounded theory approach is a relativist method to grounded theory, where the world is viewed as consisting of numerous singular truths and has recently become particularly influential.[159]

Considering the population of this study, namely busy full-time professionals, it could have been difficult obtaining follow-up interviews with all the HCPs on the long-term ventilation unit. Also, as the clinical educator on the long-term ventilation unit, the researcher's familiarity to the study population and environment could have impeded a classic grounded theory approach.[160] Consequently grounded theory was deemed to be unsuitable as the data analysis methodology for this study.

3.3.3. Case Studies

Case studies can be traced back to 1879, though contemporarily, they are more often associated with classic grounded theory.[160] Simons defines a case study as… "an in-depth exploration from multiple perspectives of the complexity and uniqueness of a particular project, policy, institution, programme or system in a 'real life' context."[161(p21)] Case study methodology tends to focus on complex situations, without losing sight of the context, leading to a holistic overview of the specific and group characteristics.[162] It has been argued that the small sample size inevitably associated with case studies may limit contextual transferability and that a case study is more of a data collection strategy than a data analysis one.[160] There is also the concern that it is often not viable for researchers to generalize from one specific case and thus there could be a risk of confirmation bias as researchers used the data to confirm their predetermined beliefs.[159]

As this study focused on all members of the multidisciplinary team working on a long-term ventilation unit, and their experience of moral distress as a whole, and the individual HCP cases will be analyzed as a group, a case study approach was not an appropriate fit for the research under investigation.

3.3.4. Narrative Analysis

Narrative analysis is an in-depth method of gathering, analyzing, and interpreting the lived narratives that people use to explain their experience, and employs interviews, diaries, pictures, letters and life experience, as the units of analysis to comprehend the way people generate purpose and meaning in their lives.[160] Emerging from the wider field of qualitative study in the early twentieth century narrative analysis has a particularly diverse approach to narrative research and may be employed by various disciplines and professions.[159]

Narrative analysis can empower and support the experiences of people using health and social services. One characteristic of the narrative researcher's role is collaborating with the research participants to provide a joint process, in some ways similar to IPA. However, narrative inquiries often require a prolonged amount of time for gathering data. Also, as with grounded theory, researchers may be inclined to label their analyzes as "narrative" when in actual fact what they are describing is thematic coding.[163] As this study is exploring the lived experience of HCPs caring for patients on a long-term ventilation unit, narrative expression is of less importance, with more emphasis placed on the actual stories the participants shared. Thus narrative analysis was not considered an ideal research method.

3.3.5. Thematic Analysis

Thematic analysis is one of the most frequently used analytical methods employed in qualitative research and is used for identifying, analyzing, and reporting themes within data.[160] In practicing thematic analysis one immerses themselves in the data in an attempt to identify recurring themes that emerge based on the research subject matter and that resonate with the research question.[164]

The outcomes of qualitative research studies may progress along a continuum representing the degree of data iteration during the analytical process, from depiction to interpretation. The use of qualitative descriptive methods such as thematic analysis may be appropriate if one requires a relatively low level of interpretation, distinct from IPA in which an advanced level of interpretative complexity is required.[165]

It has been argued that the reliability of thematic analysis can be diminished due to both the extensive number of interpretations that may develop from the themes, and the application of large amounts of data to the themes.[160] It may be possible to increase reliability if multiple researchers are coding concurrently.[166] However, this is not something which was possible for this research project. Thematic analysis also has a tendency to become too dependent on thematic demonstrations utilizing participant quotes as the main focus of analysis, to the detriment of the rigorous data analysis processes.[167] Thematic analysis was therefore ruled out as the data analysis methodology for this study.

3.4. Interpretative Phenomenological Analysis

3.4.1. Introduction

Interpretative phenomenological analysis (IPA) is an approach to experiential, qualitative, and psychological research which is informed by concepts and beliefs from three major areas of philosophy. These being phenomenology, hermeneutics, and idiography, and their ontological and epistemological relationship to IPA.[168] Considering the psychospiritual[q] underpinnings of the phenomenological process and the interdisciplinary common ground of spirituality and psychology utilized in this paper **(Figure 4)**, it was felt IPA would be an ideal analytical method to employ. As the unit of analysis and observation in this study were HCPs and the study sought to understand their differing perspectives and experience of moral distress on the long-term ventilation unit, IPA was an appropriate methodology for data analysis.

[q] "The term psychospiritual has entered psychological and religious discourse as a loose designation for the integration of the psychological and the spiritual. As a broad term it can denote a variety of positions between psychology and spirituality: a supplementation, integration, identification or conflation of the two fields. It is commonly used to describe a wide range of therapeutic systems which embrace a spiritual dimension of the human being as fundamental to psychic health and full human development, and which utilize both psychological and spiritual methods in a holistic, integrated approach to healing and inner growth."[169p738]

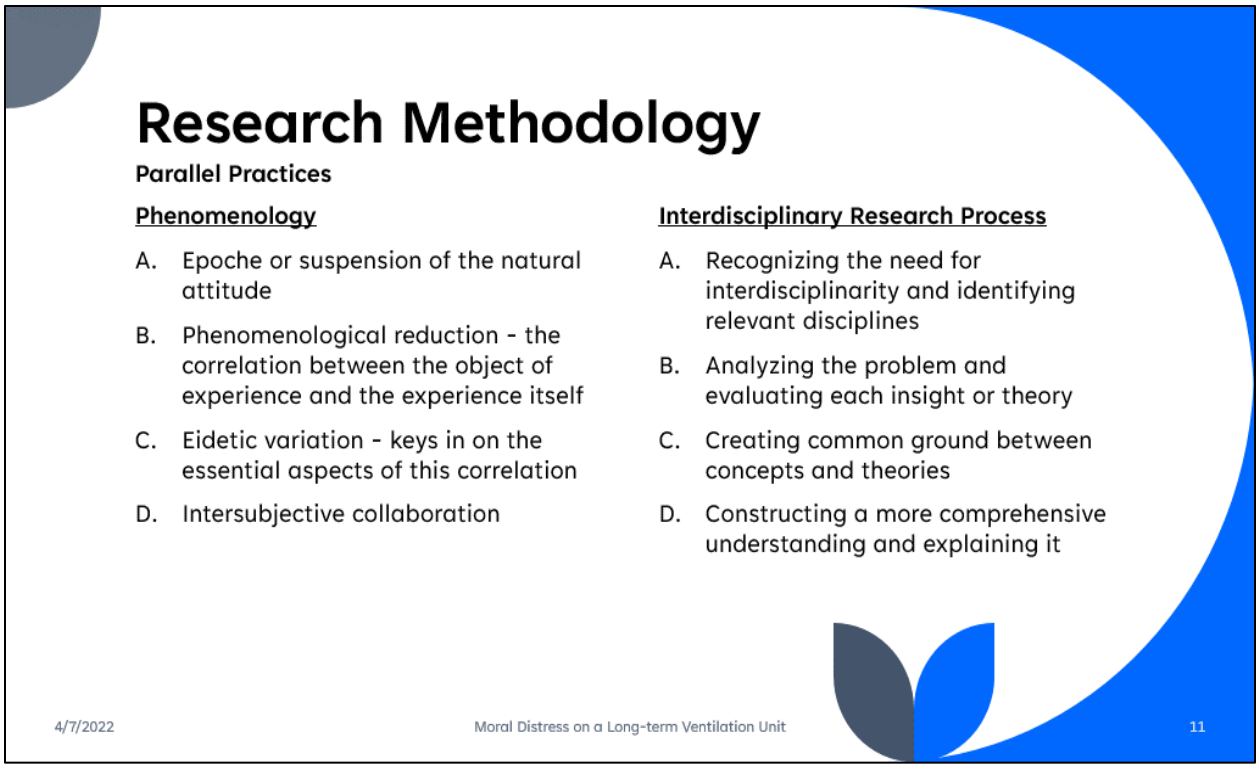


Figure 4. Parallel Practices in Phenomenological and Interdisciplinary Research Method[170]

At its most fundamental level phenomenology is simply a philosophical approach to the study of experience. Though there are many different levels and different schools of phenomenology, at their core all are interested in what exactly it means to experience life as a human being. This is especially relevant to what matters most to us as human beings and what constitutes our lived experience. One of the primary benefits to phenomenological analysis is that it gives us insight, and a tool for examining how we might make sense of our human experience.[171]

In the early twentieth century, Husserl drawing on the works of the philosophers Kant, Hegel, and Brentano, conceptualized the idea of phenomenology as a philosophy. It was revised and expanded upon by his followers, of whom Heidegger was perhaps the most influential. Phenomenology has transformed from descriptive phenomenology, stressing the actual description of people's experiences, to the "interpretation" of such experiences, sometimes referred to as hermeneutic phenomenology.[172] While Husserl was interested in the epistemological, Heidegger was interested in the ontological, the

nature of being and temporality.[171] Choosing an interpretative phenomenological approach allows the researcher to focus on gaining a deeper understanding of an experience or phenomenon such as moral distress. What is essential with phenomenology is “converting” to what is present in the experience, which is what is entailed in seeing something that was previously overlooked. The IPA method will result in a comprehensive understanding of the meanings and flavours of a particular phenomenon.[173]

Four of the key phenomenological philosophers are Husserl, Heidegger, Merleau-Ponty, and Sartre. Each of these philosophers using the core of phenomenology expanded on and developed their own different, yet complementary, approaches and outlook.

3.4.2. Husserl and Heidegger

Husserl argued that the essential origin of phenomenology is experience and thus ought to be analyzed on its own terms as it is expressed. Husserl was concerned as to how someone might come to know their own particular experience of a phenomenon.[168] Importantly, could this be achieved to the degree that one would be able to identify the essential qualities of their experience? Husserl saw these essential qualities of an experience as transcending that particular experience and possibly enlightening others to its essence. He famously stated that *we should go back to the things themselves.* Husserl's *thing* of reference is the experiential content of consciousness, and he points to the various obstacles to this insight. Husserl suggests that we should strive to see each thing in its own rights, without compartmentalizing. Husserl’s phenomenology asks one to step outside of our everyday experience, what Husserl called our *natural attitude,* to facilitate the examination of our lived experience. Adopting Husserl’s phenomenological analysis would allow one to turn our awareness from objects “out there” to a simple perception of the essential qualities – the object as is.

Husserl’s writings echo a familiar theme from ancient Indian and Buddhist spirituality, the nearest contemporary concept being the exercise of choiceless awareness, a practice popularized in the West by the Indian sage Krishnamurti.[174] In fact, it is interesting to note how much contemporary Western philosophy and psychological practice were already written about and implemented in the East, many centuries

previous. For example, mindfulness, radical acceptance, meditation, gratitude, self-inquiry, and journalling, all “new” practices in modern psychology, have been spiritual practices for centuries. The truth being the truth it needs no defense, and what is good, and works, will always appear and reappear. There is nothing more resilient than truth.

Husserl developed his phenomenological method in an attempt to discover the basis and identifying features of human experience. He suggested that we need to *bracket*, or put to one side our typically unexamined world, to concentrate on our perception of our world. Husserl saw this bracketing as being analogous to mathematical equations. Husserl's methods would proceed through a series of reductions toward a thing's essence. Husserl’s final destination was to get at the nature of consciousness itself, what he termed transcendental reduction. The issue with that is when one becomes aware of awareness, for example through extensive meditation practice, there is nothing to describe, it simply is. It is that space in which objects of consciousness, including thoughts, appear. “The eye through which I see God is the same eye through which God sees me; my eye and God’s eye are one eye, one seeing, one knowing, one love.”[175] After many years of meditation practice, I can see clearly that I am not my thoughts. My thoughts appear in consciousness. As Nisargadatta puts it so beautifully... “The perceived cannot be the perceiver. Whatever you see, hear or think of, remember - you are not what happens, you are he to whom it happens.”[176(p519)]

Heidegger was a student of Husserl. Heidegger’s philosophy was influenced by Husserl yet developed and diverged into a new phenomenological approach.[173] This approach was the beginning of an existential and hermeneutic emphasis in phenomenological analysis. Heidegger viewed Husserl’s phenomenology as too abstract and theoretical, questioning the likelihood of knowing beyond an interpretative framework. Meaning for Heidegger was of fundamental importance. He used the term intersubjectivity to underscore our relational existence in the human world. His term *being-in-the-world* is understood to be multifaceted involving socialization, self-reflection, and an affective concern. For the IPA researcher Heidegger’s philosophy sees human beings as always being in relation to other things, be that other humans or objects, and always perspectival. Crucially he views phenomenology through a hermeneutic lens.

3.4.3. Merleau-Ponty and Sartre

Merleau-Ponty is indebted to Husserl and Heidegger, sharing Heidegger's need for a more contextualized phenomenology. Merleau-Ponty develops Heidegger's worldliness of our existence, placing our individual perspective and embodied nature as fundamental to our awareness. For Merleau-Ponty science had not adequately described the mechanisms of perception and only offered a second order knowledge derived from first order experience. He pointedly states that the grief or anger of another will never be fully experienced as we will only experience it second hand. Though the intentional quality of an experience will never be fully comprehended, we may still feel a deep sense of empathy or compassion for another. He sees our perceptual and physical body sense as being more relevant than abstract or logical concepts. This relevance will be true for IPA researchers, who must be mindful that one's lived experience of being in the world may never be truly fully captured. Carper's seminal paper, *Fundamental Ways of Knowing,* presents a typology that attempts to classify the different sources from which knowledge and beliefs in healthcare practice may be extracted.[177] Especially relevant to the IPA researcher will be the personal and aesthetic ways of knowing.

Merleau-Ponty argues that to truly comprehend any human phenomenon, one must return to the phenomenon as it is lived and thus recognize the phenomenon from the inside.[86] It will be necessary to take this "from the inside" perspective when one attempts to treat moral distress and its multiple manifestations. In reference to treating moral injury in combat veterans Sherman writes that there are a variety of moral injuries suffered, requiring a variety of healing modalities. "Each soldier is unique and is unable to be repaired like a simple arm fracture that can be x-rayed and set, because moral injury hides in the psyche of the wounded… it has to be uncovered individually before it can be treated."[178(p6)] Beyond understanding moral distress from the inside, to comprehend an experience from a phenomenological point of view is to see it as something that has meaning both independently and in awareness. What Merleau-Ponty was able to do so clearly was to emphasize how deeply perception is entwined with meaning in people's experience.[86]

Sartre continues elucidating on the theme of existential phenomenology. Sartre sees the human being as a work in progress. I will never find “myself” because (hopefully) it’s a moving target. I am not the person I was five years ago, and in six months, I will not be the person I am today. For IPA researchers Sartre’s reiteration of Heidegger’s emphasis on the worldliness of one’s experience is vital. The primacy of personal and social relationships is of the utmost importance, and we must always be aware that our experience is contingent on the presence or absence of another. Thus, in IPA research our attempt to understand another’s experience will always be interpretative and relational.

3.4.4. Hermeneutics and Idiography

Hermeneutics, the study of interpretation, is a major theoretical construct in IPA research. Initially hermeneutics was employed in research around biblical texts, subsequently being used to interpret a much wider range of works.[179] Three of the main hermeneutic theorists were Gadamer, Heidegger, and Schleiermacher. Hermeneutics offers important theoretical insights for the IPA researcher. IPA is predicated on how a phenomenon appears and importantly Heidegger and Schleiermacher elucidate the relationship between our prior understanding and the phenomenon of study.

Idiography focuses on the particular, whilst engaging in the iterative process. Much of health science is concerned with the nomothetic and making general claims using quantitative methods. IPA is concerned with how a phenomenon is understood from a particular perspective, regarding a particular person, in a certain context.[180] It must also be systematic and thorough. The randomized controlled trial is excellent at predicting averages, yet the clinician will treat individuals. Though a particular treatment overall had a positive effect, it may still harm the patient sat in front of me. The aim of IPA is to illustrate, apprise, and master themes by tightly mooring their findings in direct quotes from people’s stories.[181]

Ultimately phenomenology is concerned with the ordinary everyday experience of human beings and how we make sense of that experience. IPA research is typically concerned with experience that is of particular importance to the person. Thus, IPA concerns itself with how people imprint meaning on the experiences that they have.

These experiences, though in one sense unique to each person, will also carry a sense of our shared humanness. One thing we all share in common is our perceived uniqueness. In the wisdom of AA, regarding the lived experience of alcoholism, this may be articulated as, “I may not know what you're thinking, but I do know how you're thinking.”

3.5. Research Ethics

3.5.1. Research Ethics Approval

There were four inclusion criteria for consent. If participants met the inclusion criteria, then there were no exclusion criteria -

1. Each participant must have worked on the long-term ventilation unit for a minimum of one year. Increased time and experience will glean richer information.
2. Each participant in this research must be a healthcare provider.
3. Each participant must be willing and able to openly discuss issues related to moral distress.
4. Each participant must be willing to have the interview audio recorded and transcribed (deidentified).

Research Ethics Board (REB) approval has been sought and granted from the Bruyere Research Ethics Board **(Appendix A)** and the St Paul University Ethics Board **(Appendix B)**. The researcher is a Clinical Research Affiliate at the Bruyere Research Institute **(Appendix C)**. TCPS 2: CORE-2022, Course on Research Ethics, was completed **(Appendix D)**.

3.5.2. Researcher Positionality

As the clinical educator on the long-term ventilation unit during this research study I was mindful of my position in terms of insider-outsider positionality. Particularly how my insider situation and social distance to the HCPs on the unit may affect the research.[182] My experience as a nurse gave me some insight into the lived experience and realities

of the participants, particularly the nurses. I was also aware of, and had experienced, moral distress and had suffered a significant moral injury in another healthcare environment.

I recognize that my ontological and epistemological beliefs will in many ways have influenced this research. In fact, it was my personal experience of the matters detailed throughout this study which resulted in this body of research. It was important then that I had some understanding of my positionality so that I could incorporate a reflexive approach to this research.[183]

I felt I was viewed by the participants somewhat from an insider and an outsider positionality depending on their profession and how close our relationship was. This would align with the continuum model of insider-outsider positionality.[184] Thus, my positionality required that both acknowledgement and allowance were made in locating my perspective, values, and beliefs about my choice of study design and research questions. My daily practices of meditation, yoga, and self-inquiry allowed me to incorporate an ongoing reflexive approach. This ongoing process was a needed prerequisite for me to be able to identify, construct, critique, and articulate my positionality.[183] Indeed it is practically impossible to perform any research in the health and social care fields which is value free.[185]

3.5.3. Semi-Structured Interview

A framework for constructing a semi-structured interview guide **(Appendix E)** was utilized and a pilot test interview conducted to identify the prerequisites and to formulate the preliminary interview protocol.[186] An REB approved email **(Appendix F)** was sent to potential participants for recruitment purposes.

If the HCP was interested in participating in the study, then contact details were provided for further explanation of the study. At that point the purpose and process of the research was explained, emphasizing that confidentiality will be maintained, participation is voluntary, and they may at any time decline further participation or withdraw from the research without reason. If they then wished to proceed, a consent to participate form was provided **(Appendix G)**. The consent form outlines how the data

collected will be used anonymously, stored securely, and accessible only to the researcher. The form explained the research process of questionnaire completion and recorded interview.

There was a risk that emotional distress could occur during the study as participants are asked to reveal times and experiences of moral distress. To address this risk the researcher reminded the participants that their study involvement is on a volunteer basis, and if at any time they feel that the questions or the process of the study are causing undue emotional distress they can stop the interview and continue at another time or withdraw from the study. No explanation is required. Participants had access to free confidential Family and Employee Assistance Program (EFAP) psychological support. The researcher offered support during and after the interviews for debriefing, as necessary. Participants may have been afraid that sharing some experiences in their organization could have negative repercussions for them. It was explained that, to the fullest extent possible by law, confidentiality and anonymity will be assured using pseudonyms and by altering details, so that places and persons cannot be identified. The participants were assigned a unique anonymous ID code associated with their interview recordings.

Interviews were conducted at the location and time that best suited the participants. The setting was neutral, comfortable, and without possible distractions. Throughout the interview process the researcher remained present and focused, giving each participant time and space to fully express themselves. Gentle probing, sometimes pushing, sometimes pulling, whilst not leading the participant or imposing the researcher's bias, was undertaken.[187]

3.5.4. Moral Distress Questionnaire

Approximately one week prior to the interview, the Measure of Moral Distress – Healthcare Professionals (MMD-HP) questionnaire **(Appendix H)** was electronically and securely delivered to each participant, with instructions on how to complete it. As discussed previously in Chapter Two quantitative measurement tools of moral distress, such as the MMD-HP, have been the focus of recent, and for the ethics literature somewhat heated, scholarly debates.[136,137,138,139,140,141]. By relying on self-reported

assessments, measuring instruments such as the MMD-HP, may be unable to accurately capture the phenomenon of relevance.[120]

The rationale for including the MMD-HP questionnaire was twofold. Firstly, it allowed the researcher the ability to compare and contrast the brief questionnaire answers regarding moral distress with more fulsome qualitative data. It was then possible to complement a participant's questionnaire answer with their more in-depth experience, as expressed during the interview. As Ulrich writes… "although it is beneficial to understand how often moral distress is occurring within clinical practice, a useful complementary approach would be to conduct qualitative interviews to garner insights into participants' quantitative responses. Here, one could readily tease out whether and why participants perceived a certain event as morally wrong, their reasons for rating the event as morally distressing, and what circumstances contributed to their distress."[138(p3)]

Secondly, as one of the main research questions of the study was how individuals and organizations can deal with moral distress, it allowed one to specifically look at constraints placed on an HCP and how these constraints affected the phenomenon of moral distress. Whether the constraint is real or perceived, illegitimate, or legitimate, could substantially alter how an organization, or a long-term ventilation unit, can effectively deal with the factors causing moral distress.

Furthermore, as an important goal of the MMD-HP is to specify the necessary information required in regard to the institutional factors needing reform, such constraints ought to be real and unjustified. Kolbe has argued strongly that for an effective reduction of moral distress, the instruments evaluating it should provide applicable information about these illegitimate constraints.[120] However, focusing only on illegitimate constraints diminishes analysis of the more regular and yet genuine moral distress that can potentially result from legitimate constraints,[138] such as when there's a difference of opinion between the HCP and the patient / family member, a common finding in this study.

Following the interview the recording was securely stored on a confidential Research Institute server and transcribed by the study author, who was also the primary investigator.

Transcripts, audio recordings, and questionnaires were analyzed following the iterative and inductive cycle as outlined by Smith.[188] In phenomenology, the analytical process attempts to illustrate and interpret the experiential meaning, frequently by detecting major themes, with the outcome being a comprehensive overview capturing the essential flavour of the lived experience.[186]

3.5.5. Sampling

There are no concrete rules regulating sample size in a general phenomenological study. Morse suggests six to ten could be sufficient depending on the subject under investigation.[189] Some scholars have argued that the concept of saturation is the vital determining factor to consider when deciding sample size in qualitative research.[190] However, for an IPA study the quality of interview over quantity is the axiom. Smith states that for IPA research projects at the doctoral level (i.e. for PhD and professional doctoral theses) and for other research studies in general, one will need a larger sample than the three to five recommended for a student's first attempt at IPA.[188] Indeed, he writes that a sample of ten is now seen as an optimal number for these doctoral research projects. With ten participants it is still possible to follow the idiographic steps of the IPA process whilst paying attention to each case in order. In turn the larger number also gives the researcher greater leverage in the claims that they can make, and may also increase the likelihood of the study being accepted for publication in an academic journal.[188]

Ten interviews were conducted with HCPs on a long-term ventilation unit. Most IPA studies involve a single interview involving small groups of homogenous participants.[168] Interviews were conducted with an assistant unit manager, respiratory therapist, physician, spiritual care chaplain, social worker, registered nurse (RN), pharmacist, physiotherapist, and two registered practical nurses (RPNs) who were working on, or had recently worked on the long-term ventilation unit.

Phenomenology uses criterion sampling, where the participants fulfill predefined criteria, with the leading criterion, in this study, being the participant's experience with moral distress.[186] Patton, as cited in Maza,[191] advises the use of an intensity strategy, which involves selecting participants that are best able to speak of the experience under

study, bringing their personal understanding of the phenomenon along with a desire to share that knowledge.

3.5.6. Pseudonym Assignment

Anonymity and confidentiality are crucial concerns when undertaking research, especially qualitative research involving human participants, with researchers expected to remove participants' names and assign them pseudonyms.[192] However, despite the power imbalances inherent in the researcher – participant relationship and its potential effect on naming practices, the significance of pseudonym assignment is often overlooked.

Names are not just words but are a part of the participants' cultural identity, ethno-linguistic background, and cultural legacy. Thus, assigning pseudonyms to participants without being mindful of these potential biases may exacerbate stigmas based on negative assumptions.[193] With this in mind the participants in this study were offered the opportunity to assign their own pseudonyms and reminded not to use a name of a colleague on their team. Therefore, each participant was able to determine the way their identities were represented in the study.[193]

3.6. The IPA Process

3.6.1. Introduction

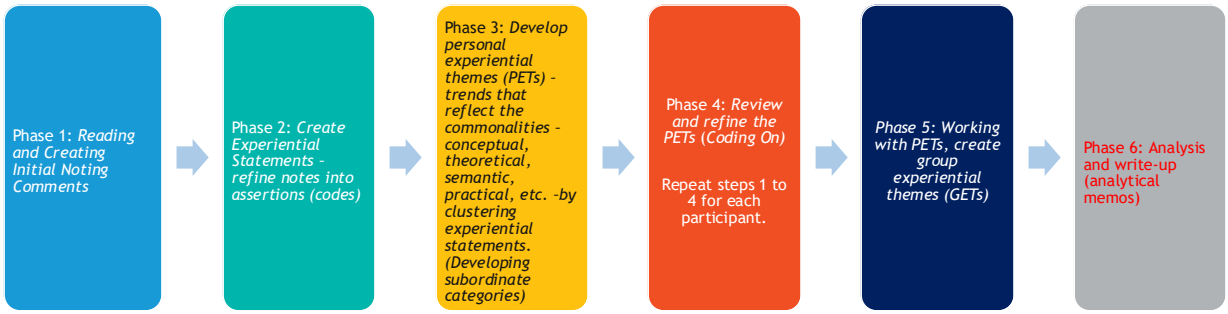
IPA has evolved around a set of explicit processes and core principles. It is a research method that allows the researcher to make sense of the experience of moral distress from another HCP's perspective. The meaning, context, and nuance expressed and interpreted are the vital data sets of the participant's experience. Due to this foregrounding and attention to detail of each individual case, it includes a commitment to an idiographic level of analytic work, which will inevitably be both objective and subjective.[188]

The sample size of this research and the one-to-one interview data are typical of conventional IPA methodology at the doctoral level, with the study design providing some homogeneity in sampling.[188] This homogeneity relates to both the phenomenon of

moral distress under investigation and the participants as HCPs caring for patients on a long-term ventilation unit. The analysis of the data will follow conventional IPA processes as outlined by Smith.[188]

NVivo© qualitative data analysis software, under licence from the researcher's university, was used to facilitate IPA data management. This provided a robust management system and audit trail. When using qualitative data analysis software, one does not submit the hermeneutic task to the logic of the software program.[160] Rather the software is used because of its efficiency at handling large amounts of data, and not as a tool which would take over the analytical process and formulate conclusions.

3.6.2. Phases of IPA Analysis



Reprinted, with permission, from IPA in NVivo Webinar[151]

Figure 5. Phases of IPA Analysis[194]

3.6.3. Phase One

In phase one of this IPA Analysis, which closely relates to steps one and two of IPA analysis as outlined by Smith,[188] the researcher analyzed one case in detail before moving on to the subsequent cases. It is vital that one continues to finish each case analysis before moving on to the next case. Smith advises starting with an interview which is interesting and engaging but not too long or complex.[194] As the first interview satisfied these criteria, and for simplicity, this is the interview the researcher began with.

A rough unedited transcript had been obtained for each audio interview using the NVivo or Microsoft auto-transcription service. Many hours were spent listening to each interview, reading, re-reading, correcting, and editing the transcription for accuracy.

Hearing and associating the voice of the HCP in the interview with the actual transcript allowed a more complete analysis.[194] While initially I found this process of transcription, frustrating, time intensive, and repetitive, it was an excellent way to begin to become familiar with the data.[195] Furthermore, it has been argued that this process is an essential methodological phase of interpretative qualitative data analysis.[196] This came to be seen as an interpretative act, where meanings were created, as opposed to a rote and mechanical application of words to paper.

In the first stage each participant, one by one, was the only focus. It was here that one needed to slow down their automatic inclination to summarize and provide synopsis. The researcher's meditation practice and breathing exercises proved helpful in continuously returning the mind to the present moment and allowing space for original thought. This was not meant to be a prescriptive process and Smith recommends that the researcher differentiates between three types of notes: descriptive, linguistic, and conceptual **(Figure 6)**.[168]

Descriptive	Linguistic	Conceptual
Basic notes to summarize the explicit meaning of what the participant has said and describe what things matter to them, in terms of objects, events, experiences, processes, locations, principles, etc. The aim is to identify the elements that structure the participant's thoughts and experiences, taking them at face value. Writing these notes ensures the analyst understands at a basic level what is happening in that portion of the transcript.	The actual words spoken, or how they are spoken, commented on. Use of pronouns, verb tenses, pauses, laughter, repetitions, hesitations, and tone, used to inform the interpretation. Metaphors may have the ability to help participants communicate and share experiences that are otherwise difficult to convey. The difference from discursive linguistic analysis is that while one is conducting a detailed linguistic analysis, it is to inform our understanding of the cognitive and affective state of the participant.	This type of commenting may take the form of questions, often at the start of the analytical process when an overall sense of the data has yet to develop. Conceptual comments typically shift away from the explicit claims of participants, and instead consider their and the analysts understanding of what is being discussed overall. Consider the participant's standpoint. These notes require reflection and the formulation of tentative ideas that are refined gradually. The purpose is to consider a range of potential meanings.

Figure 6. Summary of Exploratory Note Differentiation in IPA[194]

This was an iterative process, as one slowly absorbed the transcript adding annotations and comments, both interrogative and reflexive, in the NVivo database **(Table 1)**. This phase initially felt overwhelming at times. It proved invaluable for me to be able to make notes and annotations, thus lowering stress levels, and allowing one to focus on the data, safe in the knowledge I could return to these notes later knowing my first impressions had been captured.[194]

Table 1. Link of Stages and Processes of IPA in NVivo[160]

IPA analytical focus (Smith et al. 2009)	NVivo Process
⟷	⟷
Steps 1 & 2: Make initial notes or comments	**Open coding**
Complete immersion in the original data (interview transcripts) and initial noting. To attend to the participant and focus on the sense and meanings they make about their experiences – hopefully moving from the broad and general to specific details about events. Initial noting examines language use and semantic content 'on a very exploratory level' (p.83) and the ways the participant uses language to address issues relevant to the research questions. The aim is to produce detailed, comprehensive descriptive notes and exploratory comments on the data rather than seek out meaning units at this stage. Three main processes are involved: 1. Descriptive comments on the content of the transcript 2. Linguistic comments on how the participant has used language 3. Conceptual (interrogative and reflexive) comments to start interpreting the text. ***Create experiential statements –refine notes into assertions.***	As far as possible the participant's own words are used to summarise the sense or meaning that he is trying to convey about a specific experience from the transcript. Open codes ('nodes' in NVivo) are created for the participant's transcript. Codes aim to make a first pass at reducing the original data to descriptive phrases and notes. This is an iterative process – going through each transcript several times to code and re-code and to add comments, both interrogative and reflexive as follows: 1. Code Names capture the summary overall description of the content 2. Rich descriptive comments to provide coding transparency are included in the Code Description. 3. A journal captures reflexive and conceptual comments arising from the interview.

IPA analytical focus (Smith et al. 2009)	NVivo Process
Step 3& 4 & 5: Develop personal experiential themes (PETs) –trends that reflect the commonalities –conceptual, theoretical, semantic, practical, etc. –by clustering experiential statements. The researcher attempts to reduce the volume of data (by summarising) while retaining its complexity by looking for patterns and connections. The hermeneutic circle (Gadamer 2013; Grondin 2003; Heidegger 2012) concerns interpreting the part of the transcript in relation to the whole and the whole in relation to the part. Themes should be 'a synergistic process of description and interpretation' (p.92), reflecting both the participant's original words and thoughts and the researcher's interpretation – 'capturing an understanding'. ***Review and refine the PETs*** ***Repeat for each participant***	**Category creation** As the first step in data reduction, a new 'Category' folder for the participant's transcript in NVivo holds a copy of the set of open codes, so leaving the original open codes folder for the participant intact. Then reviewing each code in the category folder, reordering codes into broad categories (codes are added to other codes either as parent or, more usually as child codes), merged, and re-named, ensuring that new names accurately reflect coded content to allow a more in-depth understanding of the participant's lifeworld.
Step 6: Working with PETs, create group experiential themes (GETs) Abstraction: Development of a 'super-ordinate' theme for theme clusters. Subsumption: An emergent theme may naturally become a superordinate theme. Polarization: Looking for differences and similarities – oppositional relationship. Contextualization: Identifying narrative contextual elements: organising into explicit temporal, cultural and narrative themes can highlight patterns. Numeration: An indication of frequency themes appear. Function: E.g. positive and negative meanings (language / discourse analysis). Bringing it together: Summarising the development of the emergent themes from the raw data in a table or graphic.	**Category Development** Employing IPA strategies to create superordinate themes for clusters of codes. The first step is to consider how categories may be linked or reduced further into emergent themes. New names are created for category themes that reflect both the descriptive and the interpretative to create 'superordinate' themes. For example, reducing risk, avoiding risk, and taking a risk may all be clustered under one theme, e.g. 'attitudes to risk'. The aim is to reduce the original data down to between three and six themes that are relevant to the research question: consolidating codes into a more abstract and conceptual map of a final framework of nodes.
Step 6: Looking for patterns across cases. Looking at themes across participants to detect patterns. Looking for connections, do themes from one case illuminate another? Which themes are the most potent? This process can result in moving towards a more theoretical level of analysis as individual themes or superordinate themes may also reflect higher order concepts shared by all cases. The analysis so far has gone from the part to the whole. This is now reversed and the whole looked at in terms of each part. Also recurrence of themes across cases is considered. For a superordinate theme to be classed as recurrent it has to be present in at least half of cases and best case across all participant interviews.	**Consolidation and Matrix coding** Emergent themes from the participant's transcript are copied into a common 'Themes' folder where they are all merged together for the first time (leaving the category folders for each participant intact). A process of merging and further consolidation of superordinate themes may be conducted within the Themes folder. A specific type of query in NVivo (Matrix Coding) produces a table which shows participants in columns and themes in rows. This can be used to look at themes both between and within participants' transcripts (Appendix [5]).

Reprinted, with permission, from Rationale for Choice of Data Analysis Methodology[160]

3.6.4. Phase Two

Following this initial noting and annotation phase I moved to phase two of data analysis. Phase two correlated to steps two & three of IPA data analysis. In phase two general participant-driven initial coding of the interviews was undertaken. The purpose was to deconstruct the data from its initial order into original non-hierarchical general codes. Coded from the clean interview transcripts they comprised 'units of meaning' and were assigned evident names and descriptions thus providing "rules for inclusion" as the coding process proceeded.[160]

These codes in NVivo© were then reordered into broad categories either as parent codes or as child codes. Through an iterative process these codes were then merged, and re-named, ensuring that the nomenclature truly reflected the coded content and provided a fulsome understanding of the participant's lived experience.

In constructing these experiential statements I reduced the volume of detail contained in the transcript and exploratory notes whilst still maintaining depth and revealing the most important features of the exploratory notes.[188] The focus was on documenting vital data whilst maintaining a holistic perspective of the whole text. This hermeneutic circle allowed the contextual interpretation of one part of the transcript in relation to the whole and the whole in relation to the part.[197] It is a psychological axiom that in perception the whole is more than simply the sum of its parts.

3.6.5. Phases Three & Four

Phases three and four correlated with step four of IPA data analysis as described by Smith.[194(p38-45)] In these phases I developed and refined the personal experiential themes (PETs) on a case by case basis. This stage of analysis is not prescriptive, with the researcher expected to search for new and unique terms when organizing the data. Not all experiential statements were incorporated into this stage of analysis, as this was dependent in large part on the research questions being investigated. The researcher can never be reminded too often of the research questions they are attempting to answer. The purpose of this research was to explore the phenomenon of moral distress as experienced by the different categories of healthcare professionals working on the

long-term ventilation unit. What did moral distress feel like to each person and what potentially caused, or was associated with, this moral distress? Another question this research probed was how did each participant process, deal with, and heal from (or not) moral distress, at both a personal, unit, and organizational level? Importantly these questions were viewed and investigated through the higher-level interdisciplinary research lenses of 12 Step spirituality, virtue ethics, and psychology.

Within the qualitative software program, the restructured sub-ordinate categories were further broken-down, thus allowing a more comprehensive knowledge of data. Whether using software or not one ought to be working to distill and order the experiential statements into a clear and controllable pattern. Smith advises that an optimal table of personal experiential themes would contain between three to five themes, with each theme having three to five experiential statements, or for a bigger set of statements in a particular theme, this can be organized into a set of subthemes.[194(p48)]

Once again, these numbers are not prescriptive, with the researcher's goal being to prioritize quality over quantity. In the final analysis I wanted to highlight a narrative of some of the most important themes experienced by each participant. These are what would be termed personal experiential themes (PETs). Personal not because they were private but because it was at the level of the person. Not all the themes were intimate, but they all flowed from each participant being studied. They were experiential in that they directly related to each participant's experience of moral distress on a long-term ventilation unit; and they were themes because they have been removed from the particular and now expressed analytical entities wholly present within the transcript.[194]

In keeping with IPA's idiographic commitment these initial four phases were applied to each participant before moving on to the next HCP. As much as possible I attempted to view each case in particular and not look for similarities or differences between the different professions at this juncture. When there was a set of individual tables detailing each participant's PETs, one moved onto phase five, creating group experiential themes (GETs).

3.6.6. Phase Five

Phase five involved cross case analysis and the development of Group Experiential Themes (GETs) from the participant's PETs **(Figure 7)**. These GETs should be able to demonstrate a clear commitment to convergence and divergence. They ought to highlight similarities in participants' accounts of their experience, thus pointing to a high-level connectivity between them, whilst simultaneously also pointing to the particular and different ways in which each participant manifested their experience.[194(p56)] Importantly, at this stage I was not trying to present an average of the HCPs' experience of moral distress and how they dealt with moral distress. Instead, through the cross-case analysis and development of GETs, the experiences of the HCPs working within the different professions were shown to have both shared and unique features as regards moral distress and its sequelae.[188]

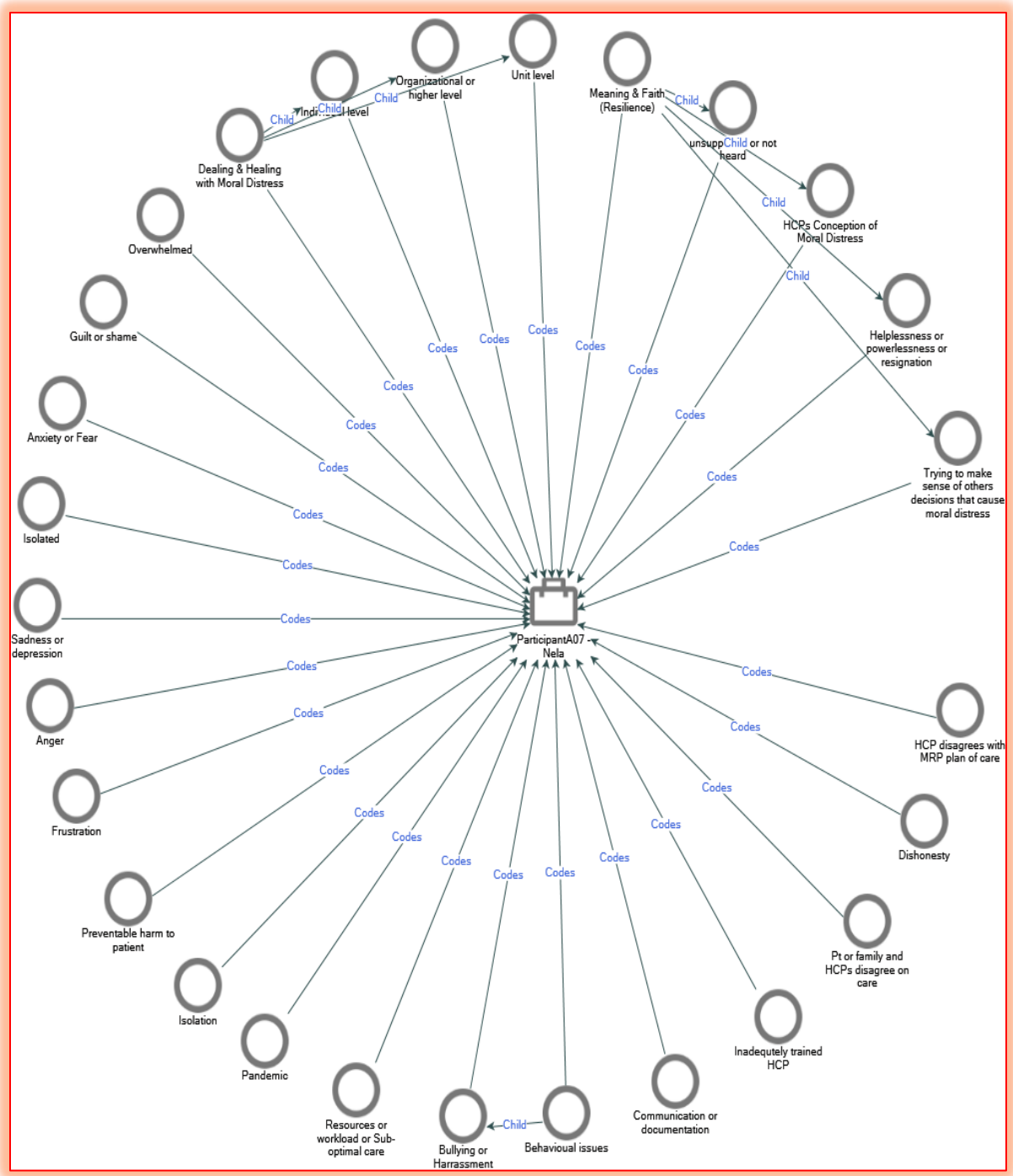


Figure 7. Visual Example of a Participant's Phase Five NVivo Codes

3.7. Summary

This chapter has outlined and validated the methodology, research design, population, sample, data collection methods, and data analysis procedures used within this study. Also provided is an evidence informed rationale for the particular research methodology appropriate for an interdisciplinary study of HCPs working on a long-term ventilation unit. As its primary focus this study utilized an interpretative phenomenological analysis in order to facilitate a fulsome and comprehensive understanding and interpretation of the experience of HCPs caring for patients on long-term ventilation.

The following chapter will present the findings of this research. The primary purpose of this research was to explore the phenomenon of moral distress, through an interdisciplinary research lens, looking at the whole multidisciplinary team caring for patients requiring long-term ventilatory support. These HCPs were drawn from the disciplines of nursing, clinical management, medicine, pharmacy, respiratory therapy, physiotherapy, spiritual care, and social work. There are many shared sequelae, symptoms, and concepts, such as powerlessness, shame, hopelessness, courage, and acceptance, between moral distress and recovery from alcoholism using the 12 Steps. The findings, discussion, and interpretation will be viewed through the lens of 12 Step spirituality and its related virtues. Analysis of each different professionals' experience of moral distress working on a long-term ventilation unit will be provided.

Chapter 4. Findings & Discussion

4.1. Introduction

In the previous chapter I outlined and validated the methodology, research design, population, sample, data collection methods, and data analysis procedures used within this study. Also provided was an evidence informed rationale for the particular research methodology chosen for this interdisciplinary study of HCPs working on a long-term ventilation unit. As its primary focus this study utilized an interpretative phenomenological analysis to facilitate a fulsome and comprehensive understanding and interpretation of the experience of HCPs caring for patients on long-term ventilation.

This chapter will present the findings of this research. The primary purpose of this research was to explore the phenomenon of moral distress, through an interdisciplinary research lens, looking at the whole multidisciplinary team caring for patients requiring long-term ventilatory support. These HCPs were drawn from the disciplines of nursing, clinical management, medicine, pharmacy, respiratory therapy, physiotherapy, spiritual care, and social work. There are many shared sequelae, symptoms, and concepts, such as powerlessness, shame, hopelessness, courage, and acceptance, related to moral distress and 12 Step spirituality. The findings, discussion, and interpretation will be viewed through the lenses of 12 Step spirituality and virtue ethics. Analysis of each different professionals' experience of moral distress working on a long-term ventilation unit will be provided.

The findings section of this IPA dissertation is far more substantial than the results section of a typical quantitative report due to the extensive verbatim transcript extracts and interwoven detailed analytical interpretations and commentary.[168] Therefore, in this IPA study there is no clear demarcation between findings and discussion, with the case findings and discussion merged into one chapter, and written in the first person perspective.[168]

Four overarching themes, Group Experiential Themes (GETs), were identified, as presented in **Table 2**. These GETs were emotions, dealing and healing with moral distress, meaning and resilience (faith), and associations of moral distress. In the

following text the Personal Experiential Themes (PETs), many of which were shared and some unique, of each participant will be explored, using extensive verbatim[r] quotations.

Table 2. Summary of Findings Group Experiential Themes (GETs) with Sub-Themes

Dealing/Healing Moral Distress (MD)	Emotions	Meaning & Faith (Resilience)	Moral Distress in Relation to -
On an Individual Level	Anger	Acceptance	Communication
Unit Level	Anxiety / Fear	Non-Acceptance	Behavioural Issues
Organizational Level	Frustration	Burnout	Dishonesty
Left a Role due to MD	Grief	Denial/Avoidance	False Hope
	Guilt & Shame	Conception of MD	Workload/Resources
	Inadequacy	Powerlessness	Physician & HCP Disagree
	Isolation	Silenced	Lack of Knowledge
	Overwhelmed	Unsupported	Isolation
	Relief	Relationship	Care Wishes Ignored
	Sadness / Depression	Pathological Hope	Moral Injury
	Helplessness	Relational Freq'	Pandemic
		Sense Making	Power Imbalances
			Patient Harm
			Disagree on Care
		Total References per GET	
351	192	255	443

4.2. Impact of COVID-19 Pandemic on Research

These interviews took place at the end of the COVID-19 pandemic in 2023. All the participants reported a large amount of distress, both emotional and moral, in relation to

[r] A denaturalized approach was used for transcription. Denaturalized transcription typically involves the informational content of the participant's speech, suggesting within speech are meanings and perceptions that construct our reality. To improve readability, interjections, stutters, pauses, repetitions, and other idiosyncratic elements of speech were removed. Any identifying speech which could have compromised the anonymity of the participant and confidentiality of the study was obscured.[198]

the measures that were imposed in response to the pandemic. In fact, so profound was the effect of the pandemic on many of these HCPs that COVID-19 could possibly have had a GET all to itself. Nevertheless, it was a significant sub-theme threaded throughout the four chosen GETs.

It was the pain and suffering I personally both witnessed and experienced during the pandemic which ultimately led to this research. Why was the pandemic so distressing to many HCPs, including myself, and what did it reveal?

4.2.1. With COVID and Not From COVID

If the summer of 2006 was the time of my spiritual awakening, then summer 2021 was the time of a cultural awakening for me. I saw glaringly and in real time the curtain pulled back to reveal that the governments, scientific organizations, and public bodies that I had trusted, such as the United States Food and Drug Administration (USFDA), had become coopted by the rich and powerful corporations, including the pharmaceutical companies, who finance about 75 percent of the USFDA's drug division.[199]

As the pandemic progressed, I became more and more uncomfortable with the reactive measures that were being imposed on the population by the Ontario and Canadian governments, many of which appeared to be causing more harm than benefit.[200] From an experimental and untested vaccine being recommended for use on healthy babies,[201] arbitrary six feet social distancing,[202] prolonged and repeated psychosocially destructive lockdowns,[203] mass quarantines, public curfews, closed public parks, ineffective cloth masks for an aerosolized virus,[204] to weeks of solitary confinement of our most vulnerable; it all felt so wrong. The catastrophic impacts of lockdowns, which will result in significant sickness and increased mortality for years to come,[205] resulted in only a 0.2% reduction in overall mortality from COVID-19.[206] Serious adverse effects of the experimental mRNA vaccines continue to come to light.[207] As seemed rational to many people, on the balance of probability, the virus which first appeared in Wuhan China, likely leaked from the Wuhan Institute of Virology, one of only a handful of laboratories in the world performing experiments on similar bat coronavirus'.[208] At the

time we were told it was racist and ignorant to believe this. Shame and fear are two methods that can be successfully employed as a method of population control.[209]

4.2.2. Moral Distress of Mandatory Vaccination

The vaccine's protection against infection diminishes significantly over time and more so against Omicron than Delta. Primary series mRNA vaccination is shown largely ineffective by five months across multiple studies, though may still provide some protection against Omicron-associated hospitalization, severity, and death, months after the last dose, but to a reduced degree than against Delta-associated morbidity and mortality.[210] For our elderly, co-morbid, and immune-compromised, COVID-19 vaccination made good sense.

In August 2021, Ontario's Chief Medical Officer of Health issued Directive #6 mandating that all hospitals implement a COVID-19 vaccination policy for their employees.[211] Mandating vaccination is one of the most formidable interventions in public health and ought to be implemented judiciously to maintain trust in our organizations and uphold ethical norms.[212]

I initially believed in mass vaccination for all, yet later as it became clearer the risk of death was predominantly with the elderly and the vaccines ability to reduce transmission waned,[213] I became more uncomfortable with the vaccine mandates. Though the mandate did not "force" an HCP to receive the vaccine it did "force" them to receive the vaccine if they wished to continue to work. A coercive policy is one that may cause a person to do what they may not want to do.[214] As the mandate was so clearly coercive a coherent rationalization must be proposed in its favour, and there must be no reasonable non-coercive alternative.[215] The bar for denying a human being their bodily autonomy must be set high. The mRNA vaccine is not a benign medicine and may cause serious adverse effects including myocarditis.[216] The largest COVID-19 vaccine safety study involving nearly 100 million recipients revealed an increased risk (>600%) of myocarditis and an increased risk (>350%) of acute disseminated encephalomyelitis (ADEM) both following mRNA injection, and an increased risk (>320%) of cerebral venous sinus thrombosis (CVST) and an increased risk (250%) of Guillain-Barré syndrome (GBS) both following viral-vector injection.[217] When the Pfizer and Moderna

randomized trial data were re-analyzed there was a 16 % higher risk of serious adverse events in mRNA vaccine recipients.[218] Recently a phase one trial of an mRNA vaccine for respiratory syncytial virus (RSV) in children was stopped due to an imbalance in cases of RSV and severe lung infection, with more cases present among the vaccine group as compared to control group counterparts, with five cases in the mRNA groups compared to one case in the placebo group. These were significant and potentially deadly adverse events. Of these six cases, five required hospitalization, including one infant who required mechanical ventilation.[219]

Furthermore, the mandate imposed significant emotional and autonomy related harms, which may have been experienced as moral distress or a sense of failure to respect one's independent judgment.[212]

I was personally heavily involved in planning and implementing the vaccine rollout in the facility I was working in. I feel pride that I was able to play a small part in vaccinating and protecting our elderly and sick patients during the Delta wave of the pandemic, as we know hospitalized elderly, immune-compromised, or obese patients may derive particularly significant benefit from vaccination.[220] However, and only in retrospect, I feel some discomfort and moral distress at the part I played in trying to persuade hesitant healthy members of staff to receive the vaccine, considering the risk of dying from COVID-19 was less than 0.01% for adults 50 or younger.[220]

There now follows the findings section, which is structured to follow the GETs identified in **Table 2**. The section is far more substantial than the findings section of a typical quantitative report due to the extensive verbatim transcript extracts and interwoven detailed analytical interpretations and commentary.[188]

4.3. Analysis & Discussion

For this IPA study there is no clear demarcation between findings and discussion, with the case findings and discussion merged and written in the first person perspective.[188]

The rationale for including the validated MMD-HP questionnaire alongside the interview guide was that it allowed the researcher the ability to compare and contrast the brief questionnaire answers regarding moral distress with more fulsome qualitative data. It

was then possible to complement a participant's questionnaire answer with their more in-depth experience, as expressed during the interview. Furthermore, as one of the main research questions of this study was how individuals and organizations can deal with moral distress, it allowed one to specifically look at constraints placed on an HCP and how these constraints affected the phenomenon of moral distress.

In conducting the interviews it was important to use the MMD-HP questionnaire and interview guide in a flexible manner. In an IPA interview these are loose guides which can incorporate ideas about the best way to phrase the questions and how to move from the general to the particular.[168] The interviewer must not rigidly follow a script, as they are listening as an active co-participant. There will often be times that it is better to abandon the structured guides to follow the concerns of the participant.[194] It is important to remember that in many ways the participant is the experiential expert on the topic and sometimes in may be that the interview needs to move entirely away from the schedule.[168]

4.4. Nursing

As most HCPs working on the long-term ventilation unit are nurses, who also spend the greatest amount of time in relationship with the patients, three of the ten interviews were conducted with nursing staff. I interviewed one registered nurse (RN) and two registered practical nurses (RPNs). In Ontario the primary distinction between RNs and RPNs is foundational education. While RNs and RPNs study within a similar framework of nursing education, RNs study for a longer time period, enabling a greater depth and breadth of foundational expertise.[221]

Most of the modern discussion in healthcare regarding moral distress can be traced back to Jameton's seminal work with nurses.[24] Of course nurses and other HCPs were experiencing moral distress and researchers were discussing the concept of moral distress prior to 1984, without naming it as such. In fact, Jameton suggests that the concept of moral distress can be traced back to the early 1900's.[28] "He refers to the writings of Walter Elmer and later by Anne Davis, Marlene Kramer, Judith Wilkinson, and others who captured the feeling nurses experienced about being distressed as a response to constraints placed on their ethical decision making. This included

disagreements with physicians about patient care and the contemporary norms that required the nurses to follow certain institutional regulations and policies rather than their own moral agency in the care of a patient."[191(p24)]

In *Nursing Practice: The Ethical Issues*, Jameton identified three categories of moral concern: moral uncertainty, moral dilemma, and moral distress.[24] He viewed nursing as the morally centered health profession and believed that philosophies of nursing, not medicine, ought to determine the future direction of healthcare. For Jameton nurses could provide true inspiration and hope for progress in healthcare, as they provided a near unequivocal commitment to their patients. Among the philosophers who rode the wave of the early bioethics' movement, Jameton was somewhat unique in that unlike other philosophers, who were medically identified, Jameton encamped with nursing.[26(p24)]

In their moral distress the nurse may feel confident regarding the right action to take and yet feels constrained, externally and/or internally. The distress of moral distress does not flow from the particular circumstances of an ethical conflict. Rather it occurs from outside the nurse in the institutional obstacles to them expressing the right action, or from inside due to psychological and social factors e.g. fear of upsetting colleagues, role expectations, timidity, and self-doubt.[26]

Presented now are the stories of the HCPs who courageously and honestly share their lived experience. The four identified GETs presented in **Table 2** will be used as thematic headings to group analysis and interpretation. To improve the flow and readability of this results section the GETs of emotions and associations of moral distress are grouped and analyzed together. These four GETs are not absolute and isolated, and there will be some crossover between the four GETs. However, using this method provided a systematic study, and facilitated cross case analysis.[194]

4.4.1. Nela RN

Nela was a very experienced RN who had worked on the long-term ventilation unit during the pandemic and for several years prior.

4.4.1.1. Meaning & Faith (Resilience)

When asked if there is anything she didn't like about her work she touches on the impact of working with untrained staff on her unit:

> Not really. I have experience with different patients. I just feel more comfortable when we are a group of regular nursing staff. That just makes me more comfortable, and I know that the stuff is being done. We can help each other. What makes me a bit more stressed is when we have untrained staff, or we're short, or we're just trying to figure out the assignment. So that can kind of make me a bit stressed, but that's about it.

When Nela is asked what she enjoys most about nursing she reveals her personal meaning that motivates her work as a nurse:

> It's just caring for people and making them comfortable. Doing, providing comfort, and knowing at the end of the day…like seeing the smile on their face and knowing that you helped them, that you did good for them, and knowing that they're feeling comfortable and good after the end.

Nela was asked when she had heard the term moral distress previously, or when she heard about this study, what was it that she understood moral distress to be. She asks if the distress can come from both the institutional constraints and also the patient and/or family and touches on how she might deal with a treatment concern with the physician:

> Does it have to be only from the institution, or can it come up maybe from the families and them? For example, we often have families that are advocates for their loved ones, and they think that the patient is not in pain and that we should not treat the pain. Even though we, as nurses like we're there rotating through the shifts, and we know that the patient is suffering. But on the other hand, they're not, they're telling us 'Oh, we don't want to give them pain medication. We don't want to sedate them.' They don't believe that they're in pain. So that's what comes first to my mind. So, it's something that we don't agree, but we have to go with it because it's a wish from the family. From the institution.... Yes, we do get a lot of doctors that sometimes require additional tests and further assessment to be done and we kind of think it's not necessary for the patient, it just prolongs the suffering. I don't know, sometimes we will have a talk with the doctor. Just a gentle talk to try to see where this is going. But oftentimes we won't interfere because it's their decision.

I ask Nela if she had witnessed a violation of a standard of practice or a code of ethics and didn't feel supported. Nela, sounding somewhat frustrated at times, recounts an experience of bullying and feeling unsupported:

> I had an experience with bullying from nurses. I mean, I know I didn't feel supported like I reported it to a manager. I did all the incident reports and everything and I had meetings with the manager, and I had meetings with the director, and nothing was never, ever done about it, like nothing about it. So, in the end I didn't feel supported. So, I do have experience.

When asked how that experience felt Nela replied that:

> Oh, it was horrible. It made me feel like in the morning that I don't want to come to work. That was my number one complaint. I was just feeling depressed. I was feeling anxious coming to work. I even I had to go see my doctor…that he gave me, like he knows me, like I'm usually like strong. But he had to give me a little break from work. So, I kind of took a break, but it was, it was not a good experience.

When asked if management knew that Nela did not feel supported:

> I told for example, my manager that I'm not gonna complain. I had for example an instance where I was harassed by a patient and from the, from bullying. I was bullied from one of the nurses. And I would say to my manager that I don't feel supported, and I won't be filling out the reports anymore because I don't get any support. So, what...what is the point? In the other instance where I was bullied by a nurse, I had a meeting with the manager. I had a meeting with the nurse. I had a meeting with the nursing director, and it still didn't solve the problem so… it just solved on its own and I feel it's more what I actually did that solved the problem, then the institution or my manager or anybody else it's just like.... Like I can't even tell you. At the end I had to be just like nice and I mean, it's not that I wasn't nice. I just had to be quiet about it and I was kind of walking on eggshells. If you ever say something to the nurse, you never know how she's going to take it, what the reaction is going to be. So, I was just kind of it's not avoiding her like I was happy if I didn't have to have a look, but the thing is, we work together every day here, so I didn't have a… but I kind of found my way how to handle, not handle her, just to kind of have trying to avoid her. Even like a small conversation but I guess that that was, that's her mentality that and for some people it's normal. For me it's not. It wasn't normal and it's not normal so to me, I solved my problem myself. I didn't find any support in the hospital.

Sadly, workplace bullying continues to exist in nursing and other healthcare professions.[222] Experiences of workplace bullying behaviour may negatively impact nurses' physical and psychological health leading to reduced job satisfaction and

increased staff turnover.[223] However, Nela displays a significant degree of resilience and maturity in dealing with this issue. It would appear that in dealing with the incivility, rudeness, and sometimes cruelty of another member of staff she eventually reached a place of acceptance. Many have found that the "Serenity Prayer"[s] is invaluable in these situations. Nela recounts poignantly how the suffering of her patients results in her own suffering and how she tries to make sense of that:

> You know, often we see a lot of stuff here, and after when our shift is done we just kind of have to put everything on the side and come out on the street and pretend nothing happened and continue with our regular activities… when you see patients suffer it kind of comes back like, not for long. I don't think about it for a long time. It just comes back as a flash. I see it in front of my eyes, and it disappears. It comes and goes… even for the deaths that are expected but I guess how in that moment our body takes it. So, a lot of times it just comes back, and it goes it...generally makes me sad because it's very hard to see somebody suffer, and we as nurses, our job is to make the patients comfortable and provide that support. So sometimes if we cannot do that either because it's not what the patient wanted, it's not what the family wishes. It sometimes makes me think what am I doing? Am I doing the right thing or it makes me feel I didn't do a good job because, but these are the things we have to keep to ourselves, just in our minds.

Fortunately, Nela is aware enough to know that she cannot keep all of her suffering to herself, and that she needs to talk and share her pain. She reports on the excellent support that is available to her and the other nurses on her unit:

> We have spiritual care, and we have the employee health program that offers support if we want to talk about it. And our spiritual care chaplain she often comes and talks to us as a group and she always says if you have any concerns, we can come and talk to her.[t] I did talk to her. I did talk to social workers sometimes, and we talked among the nurses, with each other. It helps, sometimes it helps, but I mean I think me personally I'll be OK now, but it's just sometimes it affects me in a way. I mean maybe not now, maybe in six months or in a year I get a flashback on what happened, but I think we're doing OK. We have a good support here. If I needed more support, I would contact spiritual

[s] The serenity prayer is synonymous with AA – "God grant me the serenity to accept things I cannot change, courage to change things I can, and wisdom to know the difference." It was copied and used in the letters to the early AA groups and members and over the years the prayer has been credited to almost every theologian, philosopher and saint.[224]

[t] The support available on the long-term ventilation for the nurses is the best I have seen in my career. Spiritual care provides a "Code Brew" service, where they walk around the unit with a trolley carrying coffee and snacks and provide a safe space, in the moment, for the nurses to talk about their day.

> care or get a psychologist from the employee program that the hospital offers. So, I think so far, we have a good support.

4.4.1.2. Moral Distress in Relation to - & Emotions

Referring to the MMD-HP questionnaire she had completed Nela was asked if she had ever felt pressure to carry out orders for unnecessary or inappropriate tests. Nearly all tests ordered by a physician will on some level be necessary, in that they provide information for the physician to provide the care they believe is medically appropriate. In clinical reality it nearly always comes down to a difference of opinion as to the harm / benefit ratio of the specific intervention or test. The nurse is often the one in a direct and literal flesh and blood relationship with the patient, and who acutely sees, feels, and hears the pain or suffering of the patient. Due to this temporal and physical proximity the nurse's perception of harm will differ to that of the person ordering the test. Perhaps for the person writing the order, any negative consequences may only be an abstract conceptualization, and easily rationalized as necessary for the patient's well-being:

> Well, it happens that the doctor would order a CT scan of the abdomen or lungs on a patient that we know has a poor prognosis. So, we would not as nurses, we wouldn't see a benefit of it. I see a lot of blood tests. Just CBC and usual blood test on a palliative patient, that we, let's say know that he has an infection. I've also seen a lot of chest X-rays. I've probably seen it a lot more than I can remember at the moment. Yeah, it's quite common.

When asked what feelings these situations may arouse Nela goes on to explain:

> Well, because it happened for a very sick patient. My first concern is I'm kind of upset because just picturing the transport of the patient from the bed to the wheelchair and pain that the patient is going to have on the way to another hospital to have a test. It just makes me upset because I think it's already a lot on their plate. And then just thinking what is the CT result going to change in his condition when we already know the poor prognosis. And in my head, I'm thinking maybe it's time just to provide comfort for him instead of prolonging his suffering and causing more pain.

Nela then proceeds to provide a moving account of what the experience of powerlessness, helplessness, and aloneness, in the moment, feels like for a bedside nurse:

> Upset. It's when you know, OK, we're doing something that's unnecessary, and you don't have the power to change it. So, you have to go with the flow. So, it's more like, yes, I'm upset, but I'm trying to process it myself. I'm not letting other people know, it's just how I deal with this. It stays inside me and I'm overthinking sometimes, and it comes to my mind but it's more like knowing that it will cause the patient more pain. That's it. What is going through my mind. And then of course later, like the cost of the CT scan, and the cost of the hospital, paying for the transport, everything I can think about this later, but at the moment, I'm thinking strictly about the patient. And this is the upsetting part.

Nela's simple statement of knowing that what you are doing is unnecessary, and not having the power to change the situation, satisfies Jameton's seminal definition of moral distress, when… "one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action."[24(p6)] Yet is it true to say that Nela does not or cannot have any power in these situations; that she is truly helpless? Also, is it absolutely true that what she is doing is unnecessary? Perhaps if the HCP ordering the test and the HCP carrying out the order were able to openly and safely share their perspectives it would facilitate some understanding and moral comfort for Nela.[225]

Nela recounts a harrowing story of what can happen when the patient is unable to direct their own care, and decisions fall to the substitute decision maker (SDM).[u] These situations may sometimes result in significant moral distress for the treatment team and suffering for the patient. This suffering may be viewed by the SDM as necessary and by the people providing care as unnecessary and cruel:

> There was a lady, I think she was over 80 years old. She was on a ventilator, and she had severe dementia, and she was originally on the breathing machine and her son was making decisions for her. And on top of her dementia, she also got diagnosed with cancer in her abdomen. And she was in so much pain that she would bite her lip and it would have blood coming out of her mouth. And her son, who was not even visiting her regularly, would just call once in a while, check on her, or come and visit and he was more like 'oh, I don't want her to get anything for pain. I don't want her to be sedated.' And even when he came and visited her, we would make her comfortable. I mean, as much as we could because he was refusing for her to have pain medication. He would just say,

[u] In Ontario under the *Health Care Consent Act*, *1996 (the Act)*, a substitute decision-maker (SDM) is a designated person authorized to make decisions on behalf of an incapable patient. "The SDM must be capable of making the decision (understands the information that is relevant to the decision and appreciates the reasonably foreseeable consequences of the decision);16 years of age or older; available to make the decision; and not prohibited by court order."[226]

> ‘oh, she looks good, she's comfortable,’ and we knew that she wasn't comfortable because she was in....I mean, just knowing that she had pancreatic cancer and how much pain it causes. We were just upset that we couldn't give her anything for pain. And just turning her in bed, like doing any movement, her eyes were literally bulging out with how much she was in pain, so she was on some regular pain medication, but of course it wasn't enough, and she had to go almost until the end and she passed away on the ventilator because her son didn't want her taken off the ventilator. So, she just died a natural death.

This sounds very far removed from what many would consider a natural death; though it is likely Nela intended to signify that a ventilator withdrawal would have been much kinder. When asked what this experience felt like Nela replies:

> Upsetting. It's always upsetting, but also sad. When I think about her and what she went through. Sometimes she would look, look at us with those eyes. It's like she was… I know she had dementia and sometimes maybe she was like on and off. It looked in her eyes that she wanted to tell us something and she was constantly punching with her teeth, and she was biting her lip. So even though she was nonverbal, and she couldn't move, she was giving... like we could see the grimacing and signs of pain. So, at the end, like I started, upsetting, sad and then frustrating. It was hard to see patients suffer like that.

A significant driver of both emotional and moral distress is dealing with the challenging behaviours of some patients and family members. Personally, and when talking with colleagues, the overall behaviour of healthcare system users appears to have become more intolerant, rude, threatening, and uncivil over the past few decades. This decline would appear to have been exacerbated by our responses to the COVID-19 pandemic. Why some patient and/or family behaviours have become more problematic is likely multifaceted and will require an holistic solution.[227,228] In nearly any other area of society the words and behaviour of some patients would result in the withdrawal of service, a ban from the property, and in some cases arrest by the police. This is not the case in hospital where one is simply unable to remove an in-patient and tell them not to return. Throughout my career I know of many nurses who have been spit at, slapped, or punched, with little consequence for the patient. Nela shares an example of one patient’s demeaning and abusive behaviour:

> I had a patient for a long time, who’s no longer with us and he would yell at me or it's just the way he was talking to me. It was just condescending because he used to be in military and for his family members, I guess that was OK, or for his wife too. And I did complain about that patient. I brought my concerns many

> times to the unit manager, and I was always told ‘Oh, he used to be a military.’ Yeah, I know. But it's not the way he should be treating nurses. I wasn't the only one, but it seemed like he had to pick on me that... I don't know how I felt. It was, I mean upsetting. One incident… it was just the yelling and the tone of voice when he was talking to me. But I complained about that to my manager, and it was literally every time I'd complain, my manager would go in and talk to him and she would always come out and say, ‘you did this wrong, you did this wrong, you did this wrong’ and I was just going like that in a circle. And this is when I felt I didn't have any support. So, I told my manager I won't be complaining about him anymore. I will let him yell at me and scream at me and abuse me because I don't have any support. This is what I'm gonna do now. So, I just had to deal with this.

When asked how this felt Nela verbalizes an excellent example of the ‘resignation of will’ a nurse may feel at times. Resignation of will in the context of moral distress refers to a state where the HCP feels so helpless to change a situation that they essentially give up, leading to significant moral distress. This is a negative passive state, and not to be confused with a healthy acceptance:[229]

> I would wake up in the morning. As I said, don't want to come to work or I would cry on the way home for half an hour and then have a shower and then, OK, I'm coming to work because I never wanted to call in sick or… I mean, even though I could have because mentally, I was not feeling ready. I mean, I know we were not able to pick and choose the groups because we were rotating through the groups, so I would just suck it up for my week and that's it. My manager, she knew that. I wasn't the only one. I guess he was doing this to other nurses, but I would sometimes wish I could maybe alternate the patient or a group, but that wasn't the case. We were very strict with the groups and having your pick in a certain group. So, I just took it.

The pandemic had a significant impact on Nela both personally and professionally. She tells of an encounter at the beginning of the Pandemic that left her feeling shunned and shamed:

> I didn’t have a very good experience when COVID first started in this institution, because the day the hospital initiated masking and reporting and filling out forms in this building, I had just come back from vacation abroad. I honestly reported that at the entrance that I had just come back, it was literally the day before, and at the entrance I got yelled at by the guy that was at the desk. ‘What are you doing here, why did you come here.’ There was a lot of people around me, so that felt like I was really feeling not comfortable. I was honestly disclosing that I just got back from two week’s vacation and now you're yelling at me, and I am doing everything you tell me. OK, I'll wear a mask, wear a gown, or if I have to go back home, OK. That was not a good experience. So, I

> ended up crying and calling the main person that was supervising the desk and they kind of apologized. I kind of understood because it was new for everybody, and people were just scared and stressed. And then I came to the floor, and everybody knew that I had just come back so nobody wanted to use the computer I was using. Nobody wanted to sit on the chair where I sat. If I touched anything they would come and disinfect after me. So, that lasted for seven days; it was really not comfortable to come back to work like that. I was like, I just felt unwanted, not welcome, and it was a horrible experience. Yeah, that was my start with COVID.

Nela goes on to detail the distress of having to balance the priorities of an immunocompromised partner at home and working on a long-term ventilation unit during a respiratory pandemic. Her interview highlights the messy relational ethical components of being both a nurse and a wife:

> Working on the vent unit I was just worried because my husband was having aggressive chemo' treatment at home, so I was worried about that. But I followed masking, and we were changing our uniforms and gowns and everything and for some reason I was luckily stuck. I'm saying stuck because we got divided directly with the patient's that had COVID. So, we had the COVID side and the ventilated patients that didn't have COVID. We were testing them often and there was only one that had COVID. So luckily, I didn't work with a lot of patients that had COVID. I worked with a lot of staff that had COVID but for some reason I ended up getting COVID later and from another source, not from my employees, but it was a very, very stressful time.
>
> What made me very stressed was I had a colleague who volunteered as an RN to go work extra shifts caring for the elderly in the long-term care residence, and she was just telling me how many people were sick, and older people were dying, and everything. And then when we had it on our floor... we had a few patients that were sick and a few that passed away. So, in one moment I was just like. Oh my God. Like what is happening. Like is everybody going to die because it looked like everybody's getting like, sicker and sicker. And then you hear that your colleagues are very sick. So, I was just worried because it's something unknown. We don't know what's coming, what's going to happen. It actually, it was scary, but for me it was even more scary when I got COVID because I had very bad COVID. It affected my lungs, so I experienced not being able to breathe and being sick for many days. So altogether very scary. Very scary. And stressful when you see your coworkers, you're working with somebody for a long time and then you hear, oh, she's very sick and she's having a fever for a long time. She's got small kids at home and older parents and everybody's sick. My biggest fear was I just didn't want to get COVID and then give it to somebody else that gets sicker, or you know, even dies. It was for my coworker, and it was also for my patient, and it was also for my family. I just wanted to stay safe. Kind of be sure that I am not spreading it in case I gave it to anybody.

Nela now goes on to highlight what was probably the most emotionally and morally distressing sequelae of our pandemic response, namely the enforced and prolonged isolation of our most vulnerable. I experienced this both professionally and personally. My Mum, in England, was ill with end-stage heart failure. I felt torn and trapped between helping with the pandemic response in Canada and going to be with her. She was placed on two weeks isolation when she was transferred to a nursing home during this time. Her sons and daughter were unable to visit her. She died alone on day nine of solitary confinement.[v] Anger and guilt were the prominent feelings during my grieving process.

Nela is asked how the pandemic affected her patients:

> It affected them in many ways. Number one, it's the loneliness. The hospital provided a lot of support including unit support workers, PCAs, we even had physio's, social workers, everybody helping us and being there for us. And we had a big shortage, but they were just lonely. They were missing family and visits, not just family, other visitors. So, for them it was a big loss, and we could see that emotionally everybody was depressed and down even though they had the opportunity of talking to them via FaceTime and seeing them. But for a lot of patients on our floor because they have their special routines, and family is always literally coming every day and doing their little routine. So, they were missing a lot. When COVID started spreading and when one patient got COVID from a roommate we transferred that patient to a negative pressure room. And I know his wife was visiting him the day or just 2-3 days before everything happened and she was saying 'Oh I have my cell phone; can you help me set it up because I want to be in touch with him.' So, I helped her set up the phone and everything. So, what happened? The patient got COVID and was moved to a negative pressure room so had limited access to the phone and he ended up being so sick and he passed away. So really, I don't know if he had a chance to connect with his wife and she didn't have a chance to come and see him because it happened so, so, so sudden. He was originally very sick, but it wasn't his time to die. He just died because COVID affected him so hard. So, it was all sudden for us and I think for the family too. So that was a scary, scary situation. This is where I was thinking in my head. 'Oh my God, what is

[v] I use the emotive term solitary confinement here with intent. I have found no better way of articulating what we did to our most helpless and vulnerable loved ones and the pain and suffering it caused them. The United Nations Special Rapporteur defines solitary confinement as the physical and social isolation of individuals for 22 or more hours a day and states that prolonged solitary confinement, for more than 15 days, should be subject to an absolute prohibition, noting that scientific studies have discovered some long-term psychological sequelae after only a few days of social isolation.[230] A blanket policy of prolonged and repetitive isolation must never be allowed to happen again in similar circumstances.

> happening? Who's next?' Because it just happened so fast. And the patient was doing OK a few days prior to that, then COVID hit him so hard.

I recalled with Nela my memory of the first outbreak and coming on the unit one evening and all the doors were closed to each patient's room. This was before we had any vaccines and so nobody was vaccinated. And you could feel the anxiety and the fear with all the doors closed and it felt very scary. At this point N95 masks were still mainly unavailable to the frontline staff. Nela shares:

> When it happened on the non-vented side, they were just, like there was... I could feel the anger. Almost everybody that was wearing a regular mask got COVID, especially the ones that had patients on nebulizers because at that time we were just wearing a regular mask, we didn't even have a visor. And in our heads, we were thinking 'oh if we would have had the N95 masks maybe so many nurses would not have got COVID and wouldn't give it to the patients too.' It was. We didn't know. It was a lot of unknown.

Nela was asked what one patient care experience, during her career, stood out for her as the most morally distressing. Her story clearly articulates the messiness of healthcare and the pain of feeling helpless against family wishes to prevent what felt like harm to the patient, and the sadness which haunts many nurses:

> This distress was a palliative patient and family. I remember now I'm not sure if he was aware about his diagnosis and that he's dying. He had a lung cancer. And the family insisted that even though he was dying, that we continue with the feeding, continue with the water flushes. So, this experience I will never ever forget. So, we had to do it because the family that advocated for the patient wanted this. It was a regular continuous feed during the night with the water flushes and the patient wasn't emptying himself regularly, and the abdomen, I think because the cancer had also spread everywhere. So, what I witnessed is the patient's bowel rupture. The bed was full of feces and blood. That's how the patient ended up dying. This I think is the worst experience and suffering that anybody could experience. We knew that was wrong, but we were just going with the family's wishes… and I don't… I'm not sure why that happened. Why the, I don't know if it's in the family culture or is it the lack of education that patients when dying don't really care about food, they don't feel hunger? That was one of the worst experiences. So, it's just seeing patients suffer. It's something that sticks in my head. I was so sad. I was so, I was so sad.

4.4.1.3. Dealing and Healing with Moral Distress

Nela was asked what she believed would help her, her colleagues, and the hospital deal more effectively with the causes of moral distress. In referring to the case of the patient whose pain was not well controlled she says of the patient's SDM:

> Maybe if someone got more education about disease in general, starting with the dementia that the patient had, and then if he was aware of the diagnosis. Maybe providing him with more education about disease progression. And maybe more education about pain medication. What are the medications that helps with pain? What are the medications that are sedating? Maybe frequent meetings with the doctor or maybe encouraging him to come visit more. I mean we tried to inform him, but it was hard because he was in denial. So, it looked like he didn't listen to nurses. Maybe it would have been a different situation with the doctor or maybe with the manager. Or maybe more frequent family rounds. I don't know. Maybe that could have helped to change his mind. First, we will start with the family rounds, maybe involve the social worker to kind of touch ground and see where we're at. Like how we're going to start. Often, we have the chaplain - spiritual support. Maybe assess the families at that point. Maybe more family rounds and doctors more involved telling how things are going. Maybe communicate that to the unit manager and see how we can connect on a regular basis. I know often they have a plan. What will the plan be? But sometimes the plan doesn't work. The family is just in denial and it's hard to make agreements.

Inadequate communication about end-of-life care between HCPs and patients and families is one of the most common sources of moral distress among nurses.[231] When asked specifically about how we could improve a future pandemic response Nela emphasizes the importance of staffing and having other support workers on the unit to help:

> Well, based on our previous experience we can make a plan of what we could do differently. Well, I don't know if staffing, now we have another system, would help us to schedule the shifts for the nurses, because at one point we were very short and then at the end somehow, we had regular people doing overtime. But at the beginning staffing was a big problem, we were short. I would come for work, and it would be only me and another nurse for the whole vent unit, so I had to have four or five ventilated patients where the usual assignment is two patients per nurse. So that was really unsafe, but we had no other choice. We had a social worker, physio', speech language pathologist, everybody helping us and doing other non nursing stuff. It was like that for a few days. So staffing is the number one priority just to make sure we have enough people in the on-call pool. Maybe include the calls also so just having like a backup on-call pool if it happens again. Infection control to have masks and visors and other stuff

> ready in big amounts. Because we were just using a lot of gowns, gloves. At one point at the beginning, we had those shields that we have to wash ourselves and stuff like that, so just making sure we have a lot of disposable stuff in bigger quantities. Staffing, staffing and equipment and a big thank you to unit support workers. They were a big help because they were feeding patients, they were assisting with transfers, they were a support for the patient because the visitors were not allowed, so I would include them definitely in the next pandemic plan. I don't know how we could do it without them. I don't know what else I could do. Vaccines also if it's something, that's unpredictable that we already have it, maybe arrange it so we get it earlier and stop spreading the virus.

When I hypothetically offer Nela a large budget to deal with moral distress she replies:

> If I have an unlimited budget I would have one regular doctor in the hospital during the day, I mean, we do have a doctor, and they come often, but sometimes we have like a quick question or just something we want to clarify. And I would maybe increase the orientation days for new graduates or new RNs, because I know in Europe some hospital's orientation lasts a month. Here it is two weeks. I still think it's not enough for the nurse to kind of get a sense. I would definitely offer more educational sessions, for example, at lunch hour they could have a presentation. So, for us, for example, if we have something here, I think it would attract more nurses… Maybe for us nurses it would be easier to understand the trajectory of a disease or maybe for somebody that's working on another floor it would be interesting to find out more about the vent unit and what the doctors do and what they deal with and stuff like that.

Nela's story highlights the complexities and suffering of a bedside nurse on the long-term ventilation unit. Her testimony sheds a light on the helplessness a nurse may experience when she feels forced to follow the instructions of the patient's family or medical orders which may result in pain and suffering to the patient. This sense of helplessness was also seen when Nela was trying to deal with her bullying experiences.

Could the reason for Nela's distress ultimately be an indication of her powerlessness due to a lack of support in the work environment? Caplan sees this anger and indifference flowing from the powerlessness that follows when one does not know what to do to deal with moral distress; when one does not know how to change the system or get to the root causes, anger results, often replacing concern and then followed by accommodation and indifference.[232] This indifference is not to be confused with a healthy acceptance. Most of us have some sense of a disconnection between what "is" to our reality and what "ought" to be, and for a healthy acceptance of suffering we need

to be aware that we arrive at our judgement somewhere along the axis of the opposites of “is” and “ought”.[19(p133)]

As per the Serenity Prayer it takes wisdom to know the difference as to when to accept the things we cannot change or to courageously act to change the things we can. In the daily practices of self-inquiry (Step ten), prayer and meditation (Step eleven), and the application of all the 12 Step principles such as honesty, courage, hope, faith, surrender, willingness, open-mindedness, humility, forgiveness, this skill of discernment has slowly come to many people practicing 12 Step spirituality.

4.4.2. Veronica RPN

Veronica has worked on the long-term ventilation unit and other clinical areas in the hospital as an RPN for more than 5 years. One significant difference between an RPN and an RN on the long-term ventilation unit is if the patient becomes unstable the RPN may transfer accountability to the RN. The RN would then direct the patient’s care until the patient was transferred to acute care or stabilized. Thus, the RN sometimes enjoys, or is burdened, with more autonomous decision making than the RPN on the unit.

4.4.2.1. Meaning and Faith (Resilience)

When asked what attracted Veronica to nursing, she clearly states that it was a… “desire to help people. To make a difference.” On the unit she sees herself… “ providing when I could moral support. Therapeutic communication. Just going to talk to a patient just to say hi.” When asked what she believes moral distress is Veronica replies:

> I would view moral distress as encountering a situation that you just don't... That doesn't make you feel comfortable in the reasons that it interferes with your own beliefs and values in your own personal life. For example, and for me it means because a big reason I came into health care was to help others and make a difference in their life. When I see someone that has chosen not to have advanced medical care or they just want to be comfortable and let go and those decisions aren't respected, that's a very, that's a moral, distressing, morally distressing thing for me. And also just… When I sometimes just seeing family and staff that aren't necessarily doing the best that they can to participate in making a difference in patients lives as well. It's hard to explain. Like, of course. Yeah, it is challenging.

Veronica discusses the stress of working with new graduate nurses who have little experience caring for complex ventilated patients. The literature is far more examining when it comes to detailing this subject from the perspective of the new graduate nurse. For new graduate nurses, levels of emotional exhaustion, workload and stress are seen as moderately high to high initially, decreasing over time as their experience increases.[233] Thus, it is enlightening to hear from the perspective of a more experienced nurse who would be supporting and training the new hires:

> There are some good nurses around. Probably back when we had a different manager and I remember we had around a lot of new staff on the unit, nurses. I was working with ventilator patients, and they get lots of, they got training. Well, anyone that comes to the unit, you get ventilator training, right? So, they would go through the training. However, they were new nurses themselves, like this was their very first job. So, I could see after because I worked one on one with a few of these people, and it became quite apparent that they did not have the confidence to be caring for this level of care with these patients. It takes time nursing; you don't learn it overnight. It took me a long time to even be comfortable with a tracheostomy. It's a lot of information all at once. And I did express that to management, but it was kind of just, 'well, we need the people so'... I mean, we did end up losing a lot of those people anyways. I think they found it too overwhelming. It's a challenge. It's a new, it's a, it's a whole other level of skill set. It's intimidating and it's not just the skill set that comes with it, it's the social, the psychosocial, that comes with it as well. The behaviours, these people are very sick, very trapped. Zero control. It's not just the medical side of it.

Veronica's frustration and concern with nursing graduates fresh from school taking a position on a complex ventilator unit, highlights the historic struggle in nursing to balance theory and practice. Up until the middle of the twentieth century nursing was mainly defined as a skilled trade for women, with the lack of emphasis on academic preparation fitting with the gendered expectations of women.[234] Nurses, both male and female, find it challenging to understand and apply what they learn in university to nursing on the clinical units.[235] Addressing this theory-practice gap in nursing will need a multifaceted approach which balances classroom education with hands-on clinical experience, simulation-based learning, mentorship programs, and interdisciplinary collaboration.[235] In the UK when I trained as a RN in the late 1980's, it was expected and typically done that the new graduate nurse would spend approximately a year on a regular medical or surgical floor to gain confidence and experience in general nursing

practice. This exposure to the general principles essential for clinical practice will benefit nurses, other HCPs, and patients. Veronica's testimony highlights that it is not ideal for most nurses' first position on graduating to be in critical care or a complex and overwhelming environment.

When asked how the particular psychosocial challenges of long-term ventilated patients may affect the patient's loved ones Veronica questions if it might cause them moral distress. The concept of moral distress in families is seldom contemplated on a busy long-term ventilation unit. In comparison to moral distress in HCPs the literature on moral distress in families is sparse.[236] A hospital environment is stressful and intimidating, and those agonizing feelings of vulnerability and loss of control seen in patients can also be seen in their loved ones. Families may often have to make difficult end-of-life decisions for their loved ones and their conflicting feelings will impact the healthcare team. In fact in many ways the ethical issues identified by the healthcare team, when to withdraw treatment and begin palliative care, disagreements on treatment amongst different HCPs, and how much to tell the patient and family, often mirror those of the patient and family.[237] As Veronica says:

> Having a loved one, that's ill, it definitely impacts someone because I see a lot of caregiver burnout on this unit, a lot more so than other units. Because when the patients end up on the long-term ventilation unit, they're not exactly healthy. We've got thirty total care patients and it's a lot of work. And when the families are here day in and day out I imagine it's morally distressing for them too.

When asked if she saw herself as religious and/or spiritual Veronica replies that she views herself as spiritual. Spirituality, like suffering, is a concept most people are familiar with, yet struggle to articulate.[238] For Veronica spiritual means:

> To me it means... I've always felt that I'm not, I've never been raised religious. There's no specific anything I believe in, but it's more that I believe there's something bigger than just us. It's hard because it's fairly new to me. It's hard to describe. I would say that it's having a connection to something other than yourself and the people maybe, yes, the people around, because I would consider that we're all one; we're all connected somehow. Yeah, something bigger than us or something else other than us. You know, beyond us. There's something more. I don't really have specifics. It helps me a lot. It's something that I turn to in my more difficult times now. And it's like a gentle reminder to myself and my inner self that things are going to be okay and that I can do the things and keep moving forward and have the confidence to do the things I

> need to do. Just overall it brings me a sense of comfort, honestly, that it's hard. It's, again, it's so hard to describe. It's always, I've always felt it and noticed it, but I've just started exploring it more I would say maybe the past eight months, very new.

Veronica then expands upon the practices that help foster her resilience and deal with moral distress as nurse on a complex and challenging long-term ventilation unit. She also speaks of her acceptance of the essential powerlessness inherent in her daily work life:

> I meditate, meditation and mindfulness. Bit of both and a lot of deep breathing exercises since I find them very powerful. Mindfulness. I mean that whereas sometimes I'll just, I'll take a pause and just absorb the world around me through my five senses, acknowledge my sight as well as hearing. Sometimes I will meditate. I don't have a consistent schedule, but I'll just sit and be with my thoughts. Let them go like, you know, thoughts are just like clouds. Just let them go by, recognize what's there. And I actually use those moments to kind of get to know myself a little bit better. I also use mindfulness and meditation when I'm struggling. So, when I feel triggered or upset, I'll actually go and take a moment and be with myself and go with them to try to better understand where those feelings are coming from and what they mean. Helps a lot.
>
> I also have come to understand that I can only do the best that I can do when I step into my workplace. I don't have control. I mean, I actually have control over nothing. I can only do the best that I can do when I show up to work. I have no idea what's going to happen in a day. So, I say I avoid certain situations, but really, I still have no idea what's going to happen in a day. And just knowing that I have shown myself that I have the confidence to handle whatever comes my way. And that, too, has helped tremendously. So, I know no matter where I work as a nurse, I'm going to encounter situations that are going to make me feel morally distressed. But it is getting easier... I guess there's a bit of I don't know what the word is... just encountering them over and over again and kind of start to just like push them aside. But yeah, I would just say my overall state of being has just helped me deal with morally distressing situations better.

Veronica speaks succinctly here of the peace that comes with a healthy acceptance of our powerlessness over the present facts of our lives. In 12 Step spirituality this acceptance of powerlessness over alcohol is the vital First Step for the alcoholic entering recovery. The application of the primary 12 Step spiritual principle of acceptance appears to also be of benefit when practically applied to the moral distress of the HCP. The HCP is often powerless over a hospital policy, physician’s order, or a patient’s request. Powerless yet never helpless. Ultimately if the HCP is unable to

accept or change the situation, they always have the power to leave that particular work environment, as Veronica herself did.

4.4.2.2. Moral Distress in Relation to - & Emotions

Veronica explains some differences in the patient population on the long-term ventilation unit, and how unclear goals of care may result in moral distress for her and what that feels like:

> So, I see lots of patients come to the vent unit already on a ventilator because they've been on one in acute care. And they can't come off of it, but they still perhaps might have some sort of quality of life. And that's what this unit is here for. But there's also patients that come to us where there is no quality of life. And now I would define that as an ability to communicate and express wants and desires. And at that point, when they can no longer do that, but we're still doing everything we can to keep them here, I find that a struggle. Or patients that come to us but now their disease is progressing, and they've made it clear that they don't want any advanced treatment. But then somehow it either gets lost in the system or family interference, which I still don't understand how it happens, but the patient ends up not having their wishes respected by the family. And then now they're with us. And this isn't how they wanted to live. I feel like I'm disrespecting the patient's wishes, but I have a legal obligation to perform my duties. I'm very uncomfortable. I feel, I would say I'm a very empathetic person, so I feel saddened for that patient. I can put myself in that patient's shoes and picture myself being stuck there. And it's complicated, it's, best word it's just, it's saddening obviously. Yeah. And I feel it. And I personally feel, like, disrespectful. Like I'm being disrespectful to the patient.
>
> Once information comes to light that this wasn't what the patient wanted, anything moving forward to me, it's a morally distressing thing. Because I'm in this position that I legally have to provide treatment for this patient, and I will do anything and everything I can to keep them as comfortable as possible. However, this isn't point-blank what they wanted, so it's doesn't matter how good of a nurse I am or how much or how great the care is, this is not what they wanted.

Veronica's suffering at having to provide potentially unwanted or harmful care to a patient is apparent. Her moral distress satisfies academic criteria of moral distress as - encompassing, experiencing a moral situation, making a moral judgment, facing constraints, moral wrongdoing, and moral suffering.[29] She experiences a moral situation, makes a moral judgment, faces institutional and legal constraints, performs (in her view) moral wrongdoing, and moral suffering ensues.[29] Veronica was then prompted

to share one particular patient experience that stood out for her as morally distressing. Her sadness, confusion, and frustration again appear to stem from her belief that she was providing unwanted treatment to a patient, and perhaps causing them harm:

> When I first started working here, and it was actually my very first patient. I just was like, what are we doing here? Why? Why are we keeping this gentleman alive when he's been proven to have zero brain activity? And it just it felt like it was for the family. But it just felt so wrong to him. He had a body that you had to be two people caring for him because there was zero muscle mass, so you didn't want to hurt him. And he was constantly on multiple IVs from recurrent fevers and infections. That was probably one that really stands out to me. Yeah, and even his respiratory system, like, yes, the ventilator was there, but we were constantly doing interventions to clear secretions. And it's challenging. Back to the sadness, but also some confusion too, you know, as to why this is allowed.

She reports that eventually the patient's mother passed on and the daughter then made the decision to withdraw treatment… "now that mom's gone, we can let him go." When asked how Veronica felt when they decided to withdraw treatment, she states. "Relieved for him. Happy for him. Happy is not the right word, but it was a relief for him and for the staff as well, because it was a common discussion almost every day on the unit. Why like this is so sad. None of us felt good about it."

The pandemic was a very challenging time for Veronica. She articulates the profound negative impact that nursing on a long-term ventilation unit, during a respiratory pandemic, had on her mental health:

> It was tough. It was very tough. I was very scared to come to work, but I knew it was something. I mean, I remember having this conversation with my loved ones that this is what I signed up for. Like they're saying, I always knew that this was a possibility. I fortunately didn't get sick for quite a long time, so I was here through the short staffing. That was challenging on its own because these patients require a lot of care. And, you know, eventually the body gets tired, the mind gets tired. You know, there's still so many what ifs floating around in the air. Like, I didn't know if I was going to get sick. I didn't know if patients were going to get sick or what the outcome of that would be if we did get sick. There were so many unknowns. I was also struggling a lot personally. I had been for a long time. So unfortunately, I ended up having to take some time off because I think it was about eight weeks and just for stress. My doctor, she said, 'You need to take some time off.' I actually ended up having to go to therapy for a while just to not have panic attacks to come into work. It was really scary. I'm doing much better now. Yeah.

Veronica is then asked how her experience of the pandemic may have differed from that of her friends who didn't work in healthcare. She does attempt to interpret the pandemic as ultimately beneficial though perhaps minimizes the impact it had on her well-being at the time:

> For me, I think honestly, I had more.... how do I explain this? I find I can cope with stuff pretty well, but I had gotten to a point in my own personal life that I was already on the edge. I was already at the tipping point, and I say that COVID was just the nail in my coffin. I was just waiting for one more thing to tip me over and my doctor trying to find medications and stuff at the same time, it was a sort of really bad combination. And so, I think COVID was more of a background noise than anything, fortunately. But it didn't help when I was trying to go through this process of getting healthy and improving my mental state. All that background noise with still the what ifs with COVID, that was not helping me at all. So, it's hard for me to say because I don't think COVID did affect me in that way per se. Once I was really scared... but once we got through the initial when everybody, because our unit got hit really bad and patients actually ended up doing way better than I thought they would, a lot of staff got sick and unfortunately had some long-standing symptoms, but I did see that perhaps things might not be as bad as they were sort of sounding. So that did help quite a bit. Yeah, so did take a bit of a load off my shoulders.

Documentation burden is prevalent throughout nursing, has increased over time, and may lead to clinician burnout.[239] Veronica reports the experience of many nurses who go without their meal and health breaks due to the burden of electronic documentation and how it negatively affects patient care:

> I do find the documentation can be very repetitive and doesn't necessarily capture the whole... like with the amount of documentation we do I still don't think it's easy to get the whole picture of the patient and it's just a time-consuming task. But there's ways, we do have portable computers now. You can bring it to the patient's bedside, things like that. So yeah, the charting improved a little since I first became a nurse, but I just don't know what the solution, unfortunately I just don't have an answer to what the solution would be. But yeah, I do find it feels because we are given a time frame, you have eight hours to do your job, you have a half hour to take for your break. And sometimes I know a lot of nurses that don't take breaks a lot of days, but we try to get done by that time. And I know I'll cut my break short just to make sure I leave on time. But that also means I have to cut patient care short to get documentation done on time because there's still a certain level of accuracy that we need to have for that documentation. So, I also need time to focus on it and be thorough so it can definitely affect patient care, Yeah, don't know what the solution would be either because we need to know certain things.

Sadly, as with Nela, patient and family behavioural issues are not an uncommon occurrence for Veronica during her nursing shifts:

> Yeah, we have patients that definitely have, the saying that the squeaky wheel gets the grease. And I think of certain patients when I say that phrase, especially working on the vent unit, I've experienced that because there are, you know, a total care patient. Some of them can't communicate. They can't even hit their call bells. They totally, completely rely on a health care worker checking on them. And then when you're paired with patients who do have call bells, sometimes two, and they are verbally aggressive, if you say no to them or you're not there at specific times, that becomes very challenging because especially as someone who does have a lot of empathy, compassion, I'm just trying to do my best. I do. I can tend to fall into a people pleasing mode sometimes, and those kinds of patients will pull me away from the patients that can't ask for things, call with their call bell. And I always feel guilty after those shifts, always, because it doesn't feel fair. I mean, our Ontario Health Care Act explicitly states that all patients are to receive equal and adequate care. And that's sometimes not possible. And it's simply because there are patients that are verbally aggressive, more demanding, they have higher expectations that are unrealistic. So, it can be challenging sometimes, yeah.

Veronica highlights an important theme here when communicating her guilt. It's a point I had not previously considered and did not find reported in the literature. Patients with behavioural issues not only negatively affect the HCP's well-being and are associated with moral distress - they also lower the time and care a nurse can provide to their other patients, i.e. patients with behavioural issues negatively affect other patients. This adds further strength to the recommendation for hospitals to implement effective solutions to the issue of dealing with patients and families with behavioural issues. When asked how she deals with abusive patients or relatives Veronica shares how she prefers not to work on the long-term ventilation unit anymore due to these behavioural issues:

> Usually just doesn't get to the point of abusive language and I don't think I've ever been physically assaulted by a patient, but I'm usually, I don't get to that point because I'm so focused on just meeting their needs to keep that verbal aggression down. I'm pretty good with patients. But that's also why I like not to work on this unit anymore, because just the way my personality is in those times, it's just not working. I can't give the level of care that everyone requires when patients behave like that. But I mean, there's maybe been a handful of incidents that a patient swore at me, or they've said something to me that's been upsetting. And I just, I do the standard 'that language is not appropriate or, 'that behaviour is not appropriate.' And make sure they're safe. Leave their call bell and exit the room for 15 minutes and then return. Yeah, it's challenging because on another unit like long-term care, the geriatric patient with

> Alzheimers or dementia that's saying something inappropriate to you is completely different than somebody who has their full functional brain and is just choosing to disrespect you. So, it's very different in my eyes.

Veronica's insightful delineation of how patient insight and choice affects the morality of their behaviour is noteworthy. At the center of contemporary healthcare is the role of patient choice, though it is not without some disagreement to how extensive it ought be. These differences may flow from various ways of distinguishing the value of choice, with some scholars seeing choice as valuable because it is by choosing that one makes their life their own.[240] When asked if there is a specific patient population that is most challenging Veronica says… "patients who are alert and oriented times three, however, have lost complete functionality of their body, loss of control. There's a lot of emotions that come with that. I can't imagine what that loss of control feels like. I do see a pattern." It has been suggested that patients exhibit anger in reaction to the perceived arbitrary removal of their freedoms, and to improve the mental and physical health on the long-term ventilation unit a more informed and involved role for them ought be recommended.[241]

4.4.2.3. Dealing With & Healing From Moral Distress

Veronica touches on the importance of peer-to-peer support in dealing with the powerlessness inherent in some situations that may cause moral distress… "we provide moral support to each other because we all know that we have a job to do, and our hands are tied in those situations." Morley provides concrete actions steps **(Figure 8)** which may be implemented on the unit to provide peer-to-peer support or to facilitate self-reflection for nurses experiencing moral distress.[119] These steps may mitigate the feelings of helplessness that are often associated with moral-constraint distress and will be highlighted in the recommendations in Chapter Five.

Referring back to the patient who was eventually allowed to pass on when his mother died, Veronica is asked how that situation could have been handled better. She highlights that she was not privy to all the specifics of the case and somewhat downplays the validity of her personal opinion as "only a nurse." Nursing has historically

downplayed its contribution to the health care discourse though this is slowly changing.[242] The nursing profession has come a long way from when nurses believed… "that no matter how gifted she may be, she will never become a reliable nurse until she can obey without question."[243(p394)]

Veronica suggests:

> Perhaps if there were some sort of medical parameters. I don't know the specifics into a lot of what I heard. I came to the unit when he had already been here for quite a while. I didn't know him when he still was kind of, there was, I heard movement. He could interact a little. I knew him when there was none. I never interacted with him, never saw any voluntary movement. I mean, it's such a challenging question. The answer for someone who's only an RPN. But look, parameters in place for these sorts of patients that there is nothing more to be done for this patient. There are no signs of life. And those discussions were had with the family. But again, I don't know the specifics of Canadian laws, but everyone's hands were tied because the family said no."

When asked how we have processed and healed from the pandemic Veronica articulates the moral and professional conflict that many HCPs felt in relation to the pandemic. Nurses have raised many important issues regarding their relationships with employers and patient / family members concerning the pandemic and their revised responsibilities:[244]

> Collectively, I don't think we have healed. I can see it in my colleagues. I can hear it in the way they talk about things. It's hard because we do work.... we work in healthcare, and a lot of people do listen to the news. And a lot of people say it's so hard because I feel like it's such a person by person, family by family basis, because like you were saying, we all had a completely different experience of what the pandemic was. Because I'm a healthcare worker, but on the outside, I have a lot of friends and family who either didn't get vaccinated or didn't see it as a big deal. And, you know, that was a struggle for me working in healthcare because I was being pulled from two directions and that was hard for me. So, I can see it in my colleagues. I can see that, like a patient you hear that a patient on the unit has COVID and some people are, 'well, I can't work with that patient.' So, they're very much still in fear of what happened and of it still happening. Personally, I've moved past it. I've had COVID myself. I didn't get very sick. I don't know anyone that's gotten very sick, so that's helped me move past it. However, I still, I have compassion for the people that are still very much afraid of what happened because they do have loved ones that unfortunately passed away or got very sick or they themselves did end up very sick. So, it's a very complex situation that we all lived very differently.

I ask Veronica what we can do for our healthcare systems and organizations, to improve the care of patients with behavioural issues and/or abusive family members. Veronica intuitively feels that more patient activities and more psychological support would be beneficial to both the patients and families, and the nurses. Loneliness is considered to be a crucial factor in the mental health of elderly people:[245]

> I find the use of unit support workers, the volunteers, even just having those extra people around to provide activities to these patients, keep them busy. I also think some sort of psychological assistance would benefit these patients greatly, because it's also, I can't imagine, I'm sure they get lonely in these four walls. The family can't always be there, I understand that. But there has to be some sort of in between so that they don't use nursing staff as their emotional punching bag. Right. And I know that's because we have all sorts of, like they have their attending physicians; they have any sort of specialist that they want to see in house. Maybe we should explore some psychological appointments as well.

What must it feel like to be used, as Veronica so powerfully states, “an emotional punching bag?” To know you could be spat at by a patient, yelled at by their relative, or bullied by a colleague; all in a day’s work. Veronica reports that management are doing well in helping the staff deal with families and patients, and setting appropriate boundaries:

> I think for family members, they're doing a pretty okay job. I know since our manager's taken over here, she's done pretty good even with the patients, at straightening out some of the behaviours and drawing those boundaries so that we can all work together. Because it is a fine line I understand between staff and patient. Family members there's, you know, those boundaries are even stronger. You don't respect the staff; you can't be here. And I think they're pretty good at upholding that.

When asked if she had left or considered leaving a position due to moral distress Veronica shares candidly:

> Overall good, because I've already done it. So, it felt good. It started off with, so I have, actually I'm no longer...I don't have the Ventilator on my profile anymore at the hospital. I am not to work with the ventilator patients anymore. At first that was really hard to do because it was, it would mean, it meant a change. It meant I couldn't work with some of the patients anymore because I do, I did enjoy caring for a lot of the patients. So that was hard in that respect. It was also challenging because I didn't know what my coworkers would think. Like, ‘why does she get to do something else, go somewhere else? Why doesn't she

> have to work with these patients?' And I did hear through the woodwork that that happened. But overall, I'm proud of myself for doing something in my best interest. And nursing is such a widespread field that there's so many options out there and it just didn't make sense to me anymore to keep feeling distress coming into work.

When prompted to explain what that felt like she replies:

> Anxious, uncertain. I mean, nursing is uncertain no matter what, but it felt like no matter what, I was coming in to work to be somebody's emotional punching bag. And I was going to have to work with a patient that I just knew, it was just sad to try to see them suffering. And it's very challenging. So, I just decided that this just might not be the patient population for me anymore. And I highly respect people who can continue to work with these kinds of patients and especially in intensive care units. I don't know how people can do it.

I ask Veronica, looking back on situations where she had experienced moral distress, like the ones she had described, where she had planned to protect herself and care for herself, what helped her get through those times:

> Having confidence in myself and believing in myself. And a lot of it also just comes from the therapy I've done in my personal life and the stuff I've learned there. Just learning that I come first and it's okay to be selfish sometimes and it's... also change is important. Just those little things like learning not to care what other people think. Having confidence in myself, putting myself first, self-care, all of these things that came together to push me through because I hadn't considered… I've tried to get away from this unit so many times and I just always ended up back here and working here. But then I would like it for a week or two, and then I would just get really anxious and stressed again. So, I knew that there was a pattern happening and it needed to stop.

> I keep hearing you can't take care; you can't help anyone else if you don't help yourself first. So that was a really hard one for me to learn. I just never realized I was constantly pouring from an empty cup and why I was so... I had colleagues shortly before I took stress leave, because I had spoke with my manager, I was talking to her, and she said, some of your colleagues have come to me saying that you seem agitated at work and she wanted to make sure that everything was okay. And I appreciate her doing that. But that was a wake-up call for me.

Veronica emphasizes the importance of talking to another person in dealing with and healing from moral distress. As detailed by Veronica these insights and breakthroughs, though often appearing suddenly, are slowly fermented over time and require, self-

honesty, courage, self-compassion and perseverance, principles associated with Steps Four, Five, and Ten in 12 Step spirituality.[7]

If offered a large sum of money and placed in charge of the hospital, Veronica is asked how she would help her colleagues deal with the causes of moral distress:

> I think it seems like my solution to everything, but having that accessibility to someone to talk to, I've found so much value in talk therapy and just having someone outside and that's, I was referred to the Employee Assistance Program (EAP). So that program is great. So, we already have that. But even more, it's a matter of getting people to use it too and having the ability to. Something great that they're doing right now on another unit, because we had an incident last week or two weeks ago. They've got people coming from EAP to come talk to staff one on one. And I tell them that's the first I've ever heard of that happening here. And I think that's great, honestly, to decompress over the situation and to debrief.

Indeed, it is both a matter of awareness and getting people to use it; to normalize the use of support for HCPs. In the rooms of AA, when sharing the learnt wisdom of 12 Step spirituality, one may hear that awareness plus action, equals change.

Veronica's sharing is clearly authentic, and she obviously cares deeply about nursing. Over time and with experience and suffering Veronica has begun to incorporate many evidence informed self-care practices into her work and personal life. Acceptance of what is, participation in a support community, and sharing our feelings appears to be beneficial for both the HCP suffering moral distress and the recovering alcoholic practicing 12 spirituality. For HCPs research shows positive changes from reduced work hours, expressing emotions, taking time to exercise, participating in a support group, talk therapy, mindfulness, and practicing stress reduction techniques.[246]

4.4.3. Faith RPN

Faith has worked on the ventilator unit for over five years as a RPN and has a long and varied career in and out of healthcare.

4.4.3.1. Meaning & Faith (Resilience)

When asked what attracted Faith to nursing, she speaks of the deep meaning that nursing gives to her life:

> I didn't realize as a child, I knew my older sister was a nurse, so I always like to follow her, and then I thought it was just a childhood kind of thing. Then I came to Canada and become a nurse's aide. And then I thought that was not my thing, I need to change, and I went back to school. I went to school, and I did a non-healthcare degree. I started working in a law firm and I just don't get that… I didn't feel like I belonged there. I didn't feel like I got rewarded, you know, I didn't. At the end of the day, when I go home, I didn't feel I made any difference in anybody's life. So, I went back to school, and I took nursing, after four years of university I became a nurse. And that's probably the best thing I have ever done.

I shared with Faith how I still missed bedside nursing at times and the positive difference one can make, that sense of fulfilment that I've only found in those trusting and vulnerable moments caring for another human being in the hospital ward. Faith goes on to say, almost apologetically:

> Yeah, exactly. Sometimes I feel like I'm doing it for a selfish reason. Then I know I make a difference. I feel good when I go home. I know that even if I reposition somebody from that discomfort, that much I feel I make a difference and I get rewarded. The pleasure I get, I don't get it anywhere else. So that's what makes me go into work every day.

Faith highlights how she really enjoys the fact that because the patients are on the unit for long periods of time, she is able to get to know them and how this improves the care she can provide. "So, if there is something wrong with the patient, I would be able to identify it by looking at that patient. That's why I like the vent unit, the chronic part. I get to know the patient better and it's not like acute care where you don't even know when they get discharged or if they get better." Developing this therapeutic relationship is vital to safe and effective nursing care. However, there can be many challenges with developing interpersonal and professional relationships for complex care patients with multiple comorbidities. These challenges may include families not providing full disclosure, monitoring and controlling access to their relatives for care, unrealistic demands, and verbal / physical abuse of nurses negatively altering nurse-family relationships.[247]

Faith now recounts the story of a patient who had requested withdrawal of ventilation and with whom she had developed a deep connection with due to their shared

spirituality. She highlights the challenges of simultaneously being a nurse and a fellow human being to our patients:

> The withdrawal went very well for him. Even when he come to us, he was eating. Then at admission he said that at the moment that he's no longer able to enjoy food by mouth then he would decide. So, we knew from the beginning. So, the patient had aggressive ALS,[w] and he was declining, we knew what was coming. And then it was such a....with him also, one thing so funny. He happened to be the same religion as I am, I'm Orthodox Christian and then he asked me where I'm from. And I talked to him, and he said, 'by the way, oh, I know a guy that used to work with me at a certain place. And I don't know if you know him, I think he's from where you are from. His name is so-and-so; do you know him?' That person happened to be my husband. And when I went to my husband with this a couple of months ago, we went out for dinner. 'What do you mean,' he said? I said, 'Sometimes we're trying to put as a nurse a professional boundary, and yet we can't...we're human too at the end of the day.' So, he used to talk to my husband over the phone, used to talk to him, and he used to ask me to pray for him. We used to pray. So, I developed that kind of relationship with him as well. And then but I was okay when he... decided to go. I was okay. It didn't affect me as much as other patients because I cared for this guy, he appreciated what everybody did for him. You know, he was so comfortable at the facility. He loved it here.

Faith explains how when he finally passed, she felt happy and sad at the same time. Her simultaneous holding of these feelings of happiness and sadness would appear to be an appropriate place for her grief at that time. Her acceptance was no doubt aided by her faith and the time she had to process his passing on:[249]

> It's still hard because he had very young kids. He's very young, and then he's almost the same age as my husband. And he still had a long way to go. A person who loved hiking and nature. And it was very sad at the same time for me. And also, he is no longer in pain. He was in pain. He was in pain. And he was able to decide that for himself, surrounded by his family members, and his religious man, who is a spiritual leader, was there for him as well. And he was so peaceful and so happy. And that makes me happy. I'm happy for him. He's happy. I'm happy for him as well.

[w] "Amyotrophic lateral sclerosis (ALS), formerly known as Lou Gehrig's disease, is a neurological disorder that affects motor neurons, the nerve cells in the brain and spinal cord that control voluntary muscle movement and breathing. Eventually, in people with ALS, the brain loses its ability to initiate and control voluntary movements such as walking, talking, chewing and other functions, as well as breathing. ALS is progressive, meaning the symptoms get worse over time."[248]

When Faith is asked how her religion helps her, she explains how she sees Christ in all her patients:

> It's helped me in a way that I'm Christian. In the Bible, what Jesus said was, at the end of the day, at the judgment day, when people say, ‘oh, Jesus, we didn't see you,’ when he said, ‘you didn't do it for me when I was tired, you didn't feed me when I was sick and didn't visit me.’ And people say to him, ‘oh, Jesus, we didn't see you.’ He said, ‘whatever you do for your brothers, you did it for me.’ So, every day when I take care of a patient I serve God. That's how I see it. As I said, sometimes I feel like it's a selfish thing too, because I get... If I wash them very well, if I wash them between the toes, I get pleasure... I get pleasure. I don't know if I do it for selfish reasons that's what I'm saying by that, you know when I say selfish reasons.

Although Faith finds pleasure in caring for her patients, I do not see what she does as selfish. On the contrary it is her embodiment of the selfless service of Christ which brings her joy.

4.4.3.2. Moral Distress in Relation to - & Emotions

Faith shares candidly about the challenges of caring for patients at end-of-life who have ventilator therapy withdrawn:

> Personally, what I find challenging is when patients get withdrawn from ventilators. That I find a little difficult. This is difficult for me personally as... I understand when patients are suffering for a long time and the outcome is not going to be healing. I don't know how to describe this... but there's one situation where I really, really, really questioned why I came to nursing. It was one time in my life, was not too long ago. One of the patients came from outside the city. This patient was very young. The few months prior to being a patient, she was a very well-known businesswoman, a career, in her fifties, and all of a sudden, she was diagnosed with an aggressive form of ALS and was ventilator dependent. With ALS you know, the patient can feel the pain with this. She was in excruciating pain, excruciating pain. So, this woman was in acute care outside the city. And then when the bed was available, she was transferred here. It had to be almost two hours drive from the city to here in the ambulance in excruciating pain. And then the next day we were told that she's going to be withdrawn from the ventilator. And that was for me, was very, very, very hard for me because... knowing that this patient can be in excruciating pain, nobody would come. Where is the family in that city, she doesn't have anybody here, to come here. There's no way. You know what I mean? I had to consult spiritual care and everything… that's the most distressful time for me. I feel like there was a communication break between admission here and the patient. I don't think she was fully informed on what kind of care we provided, what kind of

> treatment we can give. You know, the patient needed acute care and to be fully sedated, what we can't do here. And I feel like there was a communication barrier. And then because of that, she cannot tolerate her pain any anymore, because she's only young... and she chose to die the next day. It was like we didn't even get a chance. You know, for me as a nurse I feel like my job is to give comfort as the best as possible that I can. I know after a while we have a few patients that I witness, quite a few patients that have been withdrawn from the ventilator. That was okay with me. I took care of those patients. We gave them... and then after a while, at the end of the day you can say that is their decision. But when things like this happen, I feel like we didn't even get a chance to give them the care they deserve. What kind of… we have such a great, great, great team on the vent unit, and I cannot appreciate them enough, my colleagues. The kind of care that we give in patient communication they don't ever want to go to acute care, you know, they're comfortable here. This tells me something about us. And when that lady come in on that day... the next day was like, I had to call in sick. Two days after that, I couldn't come to work. I couldn't sleep. It really, really, really bothered me. But after then I waited a little bit longer and it was okay. After a while it was okay for me. But that wasn't the point. It was a feeling, you know, we let her down.

Faith's guilt and frustration at not being able to provide the care she wanted to her patient are all too common in these instances of moral distress. She knew what the right thing to do was, yet due to institutional constraints she was unable to do it. Her symptoms of insomnia and inability to face work are not uncommon in instances of significant moral distress such as this.[250] When asked to share what this experience felt like Faith expresses, tearfully at times:

> That was really helpless... like I'm unable to do anything... like at that point I didn't even see her physically. We just had a report about her. I didn't even see her physically. I feel like she didn't have a chance to see how we could have cared for her. We do give good care, you know, I feel like we failed her. That's what I felt personally. I felt like it got to the point that I had to express and say that next time when somebody was admitted like this we should be involved in that. In that we should necessarily be interviewed because we will give our part to what kind of care we give and based on that the patient may want to come, might not want to come. I feel like we let her down. That's what I felt personally, we let her down. And that was very frustrating for me. Very helpless... but later on, that passed... a lot of process has to go through. And then she waited a little bit but still had vent withdrawal. But I was clear after the fact that there was a conflict, but it wasn't the next day when the patient came in... it was further away from me... I couldn't get any reason for it. We were told was at that point... this is the best gift we could give. No, I didn't appreciate that word at all... this is the best gift we could give to her? You know, that's not... what we give as care is comfort. Whatever you want to do. But we give you comfort in care. To feel like you've not being cared for... if you get what I'm trying to say. My thing was

> that we didn't even get a chance, she didn't even get a chance to see us, how we cared for her. And that was very, very difficult for me. That was very difficult for me. I cared for a patient prior to that, that patient was so young and a person who was like 50, but we cared for him for quite a while. We cared for him. But finally, he decided to go. And I was okay, at least the simplest thing he said, 'pray for me.' But even that for me was I did something for him. So, I feel like I've been...I did something for him. I don't think for this lady… it just was so hard, to the point I was like, why am I in this field? It really bothered me personally. It really did affect me. It really did affect me.

The helplessness, guilt, and frustration are evident in Faith's testimony and in her voice when listening to the interview. She contrasted this negative experience with another patient who had a positive withdrawal of ventilation death; some of her frustration likely stemming from the fact that she knows it does not have to be this way. In her own words… "this was a communication breakdown." She then articulates what her definition of moral distress may sound like:

> Well, what I told you earlier about that specific patient with the distressing vent withdrawal. That was moral distress for me because that was her decision. I have to respect her decision. That's why we're here, to support the patient, whatever decision they make. If they want to take this medication we give it to them, if they don't want it, we could try to give them information why we think that the medication is good for them. But if they don't want it at the end of the day, they don't want it. I have to respect that. However, in this case, though, the moral distress for me was one of the things was the unknown, the unknown. Is she really informed? As I see it over and over again, I'm saying is she fully aware of what to expect when she comes here, is she fully aware, was it fully disclosed to her? At the end of the day, it's her decision to get withdrawn from treatment or not. I don't, I don't feel like she was fully informed, so that gives me really, really moral distress for me.

Faith is asked about her experience working on the long-term ventilation unit during a respiratory pandemic. At times she struggles to articulate what that felt like:

> Well. The fear. The anxiety, the stress that we were in was unbelievable. We are the ventilator and tracheostomy unit with all these aerosol generating procedures being done. We're doing it nonstop and just with a simple surgical mask. When we used to do IN/EX (inexoflation / insufflation is an invasive and specialized lung rehabilitation & breathing treatment) we never even used to wear a mask to be honest with you. Didn't even mask. Only we wore it when we did IN/EX and things like that. Someone coming here to talk about Personal Protective Equipment (PPE) and then the anxiety. If anybody coughs, you know that we ran around, and we run away. And I remember it was a Monday, and I was working the day shift on the ventilator side, and our manager came to us

> and said, ‘we have the very first COVID patient on our floor,’ and the mood... Everybody starts to cry... ‘I have a baby, I'm pregnant, I have a sick person at home, some sort of medication I cannot be here.’ And the stress was so high. And that evening because the word spread everywhere and on evening shift we only have four staff members. There's nobody. So, the manager was literally going around… ‘please, please, can somebody stay for this evening?’ And I said, ‘okay, I will stay,’ a few of us said we will stay. And I went on the side that that gentleman was in acute care... and we didn't realize it had already spread. And that day I was looking after a patient that was across from the patient that was sent to acute care, that was across from that room. And I didn't have an N95 mask. They had numbers and unfortunately, they didn't have my size. So, I was just wearing any N95, and I was doing an aerosolized procedure for this patient across the room, who is visibly having all the symptoms of COVID. And I have my mother living with me. I go home that day... and before I went home, I just told my husband to take my mom to my other sister's house because I don't want to... and I told them I think I was with a patient with COVID, and I have two boys. And I said to my husband, please, I don't want anybody to meet me. I'm just going into the basement and through the garage to remove my clothes and into the laundry room because I've been in contact. So then, because back then we can't even get tested, only if you feel like you've been exposed or something. Only four people were working. I called my manager, and I said, ‘I know for sure I was exposed to those couple of people that I looked after that day because the test was taking some time, and I need to be tested. I need to be tested.’ I demanded. I was off that day. I came to get tested and sure enough, I was positive for COVID. I was the very first person to get it, but fortunately I didn't even have any symptoms whatsoever. I wasn't sick at all, no symptoms, and I was able to not be able to give it to any of my family members. So, I managed.... but it was one of the hardest times and in a way how good was the work that we do on the vent unit that I learnt that nobody died. Nobody died. That patient who was patient zero was a palliative patient who died at the time... nobody died on the vent unit. Nobody died of COVID. And nobody on the ventilator side got COVID, so I think we did such a tremendous job. I feel like afterwards most of the staff got COVID, got sick. And then none of our patients got it, so you know the stress was, I don't know how to describe it.

Faith’s experience was sadly all too common for nurses working on the frontlines during the pandemic. The fear and anxiety about giving COVID to loved ones at home, and feeling overwhelmed due to the severe staffing shortages, was a daily reality for many nurses.[30] What we don’t know, we don’t know, and it can be difficult for those whose experience of the pandemic was Uber Eats and a laptop to appreciate just how horrible the experience was for many frontline HCPs. Faith gives a very graphic and moving account:

> I didn't see my mom for three months. I didn't see her because I didn't want to. My sister works from home, so she was able to take care of her. I slept in the basement for almost three months. I saw my kids on FaceTime down in the basement, and my husband. When I was sick, they just threw food by the door and left. Just like a dog, something like that. So even afterwards I didn't want to have any contact with my family members because my youngest son has allergies and pre-asthmatic symptoms. So, I didn't want to expose everybody. The children had class from home, my husband works from home. It was only me who was going out. So, the burden was... and I knew the pressure. If somebody got sick, it's going to be me who brought it to them. So that was a lot to carry, you know, it was the responsibility. And then you have to care for the patients, especially doing all these aerosolized procedures. It's not an easy thing. You can only protect as much as you can. And then yet... you don't know. You choose to change and take a shower downstairs in the basement and instead of just spending eight hours working sometimes we spent 16 hours, sometimes ten hours.

She goes on to highlight the pull she felt with the conflicting responsibility for her family and the responsibility for her colleagues and patients:

> Because you don't want to leave your colleagues knowing that it's only... normally we were like, what, 18 staff members when we ended up with only six. How could you leave? Only how could you leave your colleagues knowing that they also have family to look after? You know they have children; they have a husband; they have family too. How could you leave them? So, whether you wanted to or not you're going to stay another 16 hours, working 16 hours burnt out. You don't even have food! You know, sometimes you come without food because you're going to stay only eight hours, and you ended up staying another eight hours exhausted and come back the next day. But the team, the spirit was unbelievable. My colleagues I cannot thank them enough. You know, seriously, we have such a good team, that's what makes it great on this floor.

I ask Faith what she learnt from the pandemic. In obvious pain, and in tears, she shares:

> How vulnerable we are and how life is so precious. Because I lost a brother. My brother died because of COVID. He used to live in Montreal because he didn't like the lockdown. So, we were back home. He got COVID then he died there. And I remember... I was pissed, I mean, with him. And he was telling me… 'You know, my oxygen was 86% and I couldn't reach the call bell. Because I was in an isolation room. I couldn't see the nurses.' And to me, when I came the next day and I was talking to him, I was looking at the patient that I was taking care of, and then I was performing the IN/EX and checking the oxygen sats and it was 86% just like my brother and I just like said, 'what is this?' And I couldn't care for that patient, and I had to call one of my colleagues to come in and take over. Somebody else can just take over... I just needed a little bit of a break

> from here because I felt like I wouldn't be able to take care of my brother at that time... But in a way, I'm so happy I was there for somebody else. I wish my brother had had that opportunity as well.

During the interviews I remember feeling sadness at times. However, it was often on reflection, when listening back to the interviews, alone in my office, I would be hit with waves of intense grief, sadness, and sometimes anger. After Faith had shared with me the loss of her brother during the pandemic I shared with her the loss of my mum.

> That's tough... my mum died at Christmas 2020 in England. I knew she was dying, and I felt guilty because I was leaving the nurses. I knew I wanted to go say goodbye to her. I felt guilty about taking too much time away from work because I knew how desperate we were. And when I went home in November 2020 for a week, and I knew it was the last time I was going to see her. So, we spent a week together. And we just talked and watched TV and had fish and chips just... and it was beautiful. And I said goodbye to her, and I knew I wasn't ever going to see her again... and then she died on the 27th of December. But I felt so helpless because unfortunately, she died... she'd gone to hospice and then got a little better and then they sent her to a nursing home. And then she had to be on isolation for two weeks. So, on day nine of isolation, what she described as like being in prison, they found her dead. It broke my heart.

Listening back to my words, alone in my office, I was racked with grief and in tears. However, hearing my voice speaking this pain was very healing and cathartic.

Faith is asked if she had ever worked with other HCPs who were not as competent to provide the care that she felt ought to be provided, and what that felt like:

> It has happened quite a few times actually and sometimes it's very hard, and you try to help. Some people are open to learning. There are skills that I didn't know that I learned along the way. And there are skills also that I know. It doesn't mean that you're incompetent or anything just because you don't know. You don't have that skill, per se. Some receive it well, some not. Especially if I find that it is compromising the patient's care outcome. I went to the manager and spoke with the manager. In fact, at one point I even, I think she probably came and talked to the nurse. She knows nurses who are, especially when they're only doing night shifts, when they don't practice those skills. So, in that sense yes, I have.

> That is a hard one. I feel that the patient is not treated. I think often what I do is, personally I always focus on the patient, put myself in the patient's shoes. That could be my mom, or it could be me, or it could be any of us. And because our patient age group, this population is from age 21 to whatever. So, it could be any of us. How would it be if that patient was my mom? That's what I do often.

> So, for instance, last time when one of the patient's catheters was in the wrong place and there was a normal saline irrigation. And it was hard for me, I spoke to that specific nurse before, and then again, and went straight to the manager and I said, ‘please, maybe we should teach the skills for this person.’

4.4.3.3. Healing From & Dealing with Moral Distress

Faith had mentioned, in reference to the distressing case of the female ventilator withdrawal patient in pain, that involving the bedside nurses in complex ventilator admissions could provide a more balanced picture to potential admissions of what care the nurses can and cannot provide. This speaks to an issue I have seen throughout my career; namely, as the decision makers are moved further away from the place that the decisions impact, it leaves more room for misunderstandings and misaligned expectations. Having the input of those at the bedside, and nurses dedicated to the admission process, can positively impact the pre-admission process and will be one of the recommendations from this research.[251]

Faith is asked, if given a magic wand, or $1 million, to help reduce the amount of moral distress that the team has to face, what improvements would she make:

> Oh! Other than the SPD supplies, the supply system, the shortage of supplies we need! One thing that I wish was, I wish, it just breaks my heart to see the patients not get out of their room, some of them. If somehow some sort of entertainment. It could be a spiritual person that can pray for them or a group to sing a song for them, whatever. Just if we identify, what I always wish for, when we see a patient, for instance, coming at 80 years old, what we see is this patient. That patient might be a doctor who has been, you know, treating somebody. It could be a farmer who feeds so many people. It could be a janitor who has cleaned the schools where our kids go. I would like to have a little snapshot of that patient's life. Just a little frame in the room, though, with a picture that would give a lot of perspective. I always wish that you will give us a little bit of what this person is beyond what you see in the bed. This person was somebody that contributed to society, this person could have been in a World War who fought against the Nazis.

I share how when I had previously worked in an ICU, we had done just this. It was very easy to lose sight of the human being when all you would see are lines, monitors, ventilators, pumps, etc. It would jar me out of my mechanical and rational frame of mind

when caring for a patient in the ICU on seeing a picture of them fresh faced and bright-eyed playing hockey with their child. Faith recounts the story of one particular patient:

> A medical doctor and his wife, an old lady, used to come to visit him all the time. This was a guy who we always had to have a seatbelt as he's prone to falling, and yet at one point he was looking after so many of his own patients. He healed so many people. So, I think we should be able to see beyond this physical thing right now. That person contributed. For me, in some way or another it would give some perspective. I think, that's my wish.

Faith's sharing reveals an authentic nurse who cares deeply about her patients and finds resilience and faith in her religion. However, even with the strength she gets from Christ, she did share that the moral distress she experienced during the traumatic ventilator withdrawal of the female patient caused her to consider leaving her position. Thankfully for the ventilator unit, and thanks in no small part to the spiritual care supports on the unit, she did not. When asked how we could prevent an incident like that happening again Faith reiterates the importance of involving beside nurses at pre-admission. "The nurses will have much more understanding of how the floor runs and goes than the admission office. I think they would come with a good understanding of how the floor works and runs. You know, we take pride seriously. We take pride on the care that we provide. We do." Indeed, they do.

All three of the nurses in this study describe the multitude of disparate factors that may result in or confound the experience of moral distress. They share the value of story-telling, peer-to-peer support, finding strength in their spirituality or religion, and the vital importance of clear communication; virtues and principles at the heart of 12 Step spirituality. These modalities may help to transform their moral distress into opportunities for personal growth and positive change and form part of the recommendations offered in Chapter Five.

4.5. Social Work

The themes and experiences of moral distress often share similarities between the various healthcare professions. However, due to differences in context and role responsibility the phenomenon of moral distress may be felt and expressed differently.[252] For some healthcare professions, particularly social work, the experience

of moral distress has often-times not been articulated or has been identified as something different.[253]

As members of the multidisciplinary healthcare team on the long-term ventilation unit the social workers are vital to the psycho-social well-being of the patients, families, and often their colleagues. The social worker is frequently asked to intervene during times of amplified emotional and moral distress. Their expertise is critical to alleviating disputes between patients, families, and the healthcare team on the long-term ventilation unit. Subsequently these conflicts and emotionally charged encounters are ripe for the development of moral distress. However, there is very little research investigating the experiences of moral distress in social work, which has resulted in difficulties in naming, addressing and alleviating social workers' moral distress.[253] Fantus reminds us that explicating these sources of moral distress will be of vital importance in informing practice, education and research in social work.[254]

Understanding the professional differences between social work and the other healthcare disciplines on the long-term ventilation unit will be important when trying to address and mitigate moral distress across these various disciplines. In social work moral distress has not yet been effectively discerned from other negative experiences in social work such as burnout and occupational stress.[254] However, burnout and occupational stress do not necessarily arise from moral conflicts. Often they are reactions to common workplace restraints and pressures rather than inherent value conflicts.[254] Furthermore, concepts such as disjuncture, ethics-related stress, and professional dissonance appear in social work literature when describing issues that on the surface appear comparable to moral distress.[254]

4.5.1. Sarah – Unit Social Worker

Sarah has worked in healthcare for nearly ten years, with the past four as a social worker in the hospital. She spent two years working on the long-term ventilation unit during the pandemic which adds richness and depth to her experience of moral distress.

4.5.1.1. Meaning & Faith (Resilience)

When asked what attracted her to social work Sarah shares how she had been personally touched by the profession:

> I think at first it was actually that it was quite a generalist degree. That you could work in healthcare or policy, mental health. So, it seemed quite general when I first started pursuing social work but then ended up really enjoying mental health work and healthcare work, which kind of drove me into that direction. I think I'm someone that's benefited from social work intervention in the past and have been helped by social workers which guided my career path in some capacity. I find it something that you can be quite broad in your scopes with which lends to a lot of different rich practice experiences, which can be nice when you've assumed a role where, yes, you're a social worker, but you can learn and try new things constantly in the role.

Sarah speaks to the importance of advocacy in her role. “I think there's always space for advocacy and I think that's something that social workers do quite well and something that I think is an important part of our job is that we advocate for people when they're not able to advocate for themselves or need assistance in doing so.” When asked what she believes moral distress is Sarah highlights how it may be impositions on our personal morality that cause moral distress and also the constraints imposed by one’s College or regulatory body:

> I think when you're presented with a situation where you're enacting something that maybe doesn't align with your personal ethics, or even some of your beliefs. I know for a lot of folks I've seen that since there are religious beliefs that may contrast some of the things that we do in healthcare. I would say moral distress too for me is, I would say that's a big one where you're enacting things that maybe go against your personal beliefs and College, or professional body that you're assigned to work for.

When Sarah is asked where she draws her strength from, or what guides her in her work, she shares:

> I think heart would be appropriate, or intuition, like I feel I always kind of have a good sense of what I feel is right, and what I feel is wrong. May lead me to troublesome places at times where I'm having to speak to my manager about things that I've seen or speak to the manager or whoever it may be, but I do think that it's an important piece and I would say for people on the vent unit, some of them have no one. So, they need an advocate. I don’t know where I get my moral courage from. Maybe just from having a big mouth, I don't know. I

> feel sometimes I'll see things that I just, just feel unjust. Maybe that's why I feel so upset about this Palliative Care Unit renovation. And not doing the other side of the unit, but there are times where I just feel… I think equity is something that I value across my life and when I see people that need more assistance or have a right of access to more assistance to be able to do things that we know that they're capable of that aren't given those opportunities, I find that to be really frustrating.

I ask Sarah if she would define herself as spiritual or religious. She highlights the importance of having a realistic acceptance to the intractable challenges inherent when working on the long-term ventilation unit:

> I would say spiritual more so than religious, but I was raised Roman Catholic, married in a Roman Catholic church. So, something that I've been around my whole life. I think for me spirituality means believing in a higher power. Being kind. Being nurturing. Having a voice when needed to speak up for those that can't. Those are the parts of spirituality that I think that I take. And then also just accepting what you have as part of life and just sort of going through the motions of each time. And maybe that's how I found solace through the pandemic. That's just what we had in that moment and there was no changing it, and we had to work with what we had.

Sarah is articulating here a healthy acceptance of her powerlessness of what is. I ask her how she might develop moral resilience, and she emphasizes the importance of supportive relationship:

> I think I get moral resilience from my team. Definitely the people that I work with, the people that I work for, the patients that I serve, that I show up to work every day to support. So, it's probably my family and friends. I would say I have a really strong support network outside of the hospital, outside of working in healthcare. Which makes it so going home each night is quite easy. Being able to recharge my batteries is easy.

4.5.1.2. Moral Distress in Relation to - & Emotions

The pandemic was a particularly challenging time for Sarah, as it was for many other frontline HCPs. When asked what a typical day may look like on the unit for her, she provides a rich explanation of what a social worker may do in a hospital. She also highlights the impact that limiting people's mobility had during the pandemic:

> With COVID it was really different because I felt like a lot of my days, especially at the start of the pandemic, well, maybe just throughout, was spent working to

> find ways to connect patients with family members when visitation was being revoked. Looking to find ways to connect patients who were in need of mechanical ventilation and obviously in need of quite a significant amount of nursing care throughout the day, with the outside world. Where people who had vent trained family members may have been able to go sit outside or leave the unit, they were now sort of stuck in one space in perpetuity.

She also touches on the importance of routine and ritual in a patient's life. This is especially pertinent to patients on the unit who already have limited autonomy, including both decisional and executive autonomy.[255] Once again, the need for mental health supports is noted:

> So, I found a lot of times it was working to find ways to support families and finding a sense of normalcy in their life, which I think a lot of the patients and families on the vent unit have found even given the quite profound need for medical intervention that they have, they still have their normal routines. The things that they do that bring them joy and I think a lot of that was sort of stripped when we were really in the throes of COVID and rightfully so, as we were trying to protect people who are already sort of vulnerable from a respiratory standpoint. So, a lot of that work and then I would say general psychosocial caring for patients and families on the unit. I wouldn't say that we were doing any kind of active psychotherapy, just given the resources on the unit, but I do think that there's still a profound need for some additional mental health supports on the unit. Yeah. And then I would say I did a great deal of sort of liaising with the medical team, the allied health team and families and helping to, and I find social work does this across the board, helping to put things in layman's terms, helping for families to understand actually what's happening with their loved ones in a way that's maybe a bit more approachable than a lot of the medical jargon that we use, especially on a vent unit. Like I had to spend a lot of time learning what was being said when I first started working up here too.

Like other HCPs in this study Sarah expresses guilt at the different freedoms she enjoyed, compared to her patients, during the pandemic. When asked how the no-visitation policy and the resulting isolation affected her, she shares:

> I found that was something I really struggled with and that every day I got to go home and see my family and the same rules that were applied to patients weren't being applied to staff. So as things were being lifted in the community, I think some of our policies remained quite firm and for reasons for infection control and protecting the folks that are on the unit. So, it was hard for me to be able to leave freely at the end of the day and know that my patients would be, I don't want to say stuck but I'm sure for a lot of them they felt stuck on the unit. Not even able to go see their friends that they've made on the unit or people

> that they would have talked to before. So, I felt a great deal of guilt, I would say in that time where I still got to leave. And in the midst of COVID, when we are really in it there wasn't a whole lot to do but at least I could go to the grocery store and pick out my groceries and spend time outside and my patients weren't able to do that. I did feel a great deal of guilt in that. Like my patients sometimes when you work on a unit for a long period of time and it's always the same people, they'll ask you, 'how was your night? What did you do?' and I would not want to say because they weren't given the same liberties or the same… COVID had a much more significant effect on their life than maybe it did mine. Not maybe, it did have a more profound effect on their life than it did mine.

One of the questions on the MMD-HP questionnaire asks the HCP if they have witnessed other HCPs giving false hope to a patient or a family. It is very pertinent to note how Sarah suffered significant moral distress in relation to a specific experience reported on by other colleagues. Multiple participants in this study, from different professions, reported significant moral distress from their perspective relative to this situation. I ask Sarah about her having witnessed this false hope. She struggles to choose her words carefully and respectfully whilst simultaneously conveying the suffering that was caused:

> There was a time where we had a newer doctor on the vent unit. The doctors that we typically have up here have been with us for a long, long time and understand, maybe the trajectory of what it looks like for a chronically ventilated patient. There was an instance where a new admit had come in and I felt the doc that had been involved in this case, that's no longer working at this hospital, had very... I'm trying to think of the right word for this. Their boundaries with this patient were not very firm and would spend a great deal of time with one patient in particular, as opposed to the entire caseload that they were supposed to be seeing. And would make recommendations that would go against what the care team had said would be most appropriate for the patient. And would constantly request or write orders for things that go beyond the scope of what as a team we could provide. I think specifically more so for physiotherapy and telling the family, 'oh, if they did more physio', they'd be able to get better,' and it was the impression of the physiotherapist and the occupational therapist and the respiratory therapist that this person was probably at their baseline. And I felt both the patient and the family were given this false sense, that if they just kept working harder, they would improve, and it didn't happen in the time that I worked on the unit. And I think in many ways contributed to this family's prolonged sense of grief. I felt they were postponing grieving, not the loss of their loved one, but their loved one's functionality and for the patient themselves, they kept hanging on to this, and I felt they were just waiting to grieve, or they were waiting to get better before they felt grief, and I think we postponed probably a really natural part of what this person's life may continue to look like now.

Sarah is asked to expand on what that felt like to witness and be a part of. She expresses that she felt angry. It is well documented that nurses suppress anger and this was especially true during the pandemic.[256] It would appear from a review of the literature that suppression of anger is not a highlighted phenomenon of social work. Some authors argue that Western male philosophers have traditionally dismissed women's anger, and canonical Western philosophy has historically privileged men by connecting male subjectivity to divine logos while simultaneously diminishing the status of women by the linkage of anger.[257] However, as both nursing and social work are predominantly female professions, this difference could perhaps be due to the significant psychotherapeutic component of social work practice and training, in comparison to nurse training:

> How did that feel? I felt really, actually, now that I am removed from it, I realized now I felt really mad about it and I think that was maybe the general consensus on the care team is that we felt that. Especially I would say for the respiratory therapist, that their clinical impressions were quite clear of what we could expect of this person. And that wasn't being listened to by the physician at the time. So, I felt pretty mad, and I felt hopeless for this family. I felt they were stuck, and I felt so much was being put on to the patient. That if you just try a little harder this might, you might not be chronically ventilated any longer and it's just… It's not saying that it doesn't happen, but I would say it happens very infrequently where someone that's chronically ventilated suddenly doesn't need the ventilator anymore. At least in my experience.
>
> That one was definitely the most significant one. We see there's always a space to hold hope with patients, but I think one of the things that we need to do, and I think as social workers I need to do, is help people have the information they need to make informed choices. I find usually I don't feel... I don't find it as challenging to push up against doctors or push up against care teams, when I feel that patients aren't getting the information that they need, but in that instance, I felt no matter what we said we were kind of always opposed.

It is interesting Sarah uses the word hopeless when describing this situation. Though hopeless and helpless are often used interchangeably I would say in this case her choice of words had significance. Whereas helplessness can be feeling powerless to act, speak, or advocate, hopelessness is about losing hope for the future, as Sarah had.[258]

I now ask her if she has been involved in following the family's insistence to continue aggressive treatment, even though she didn't believe it was in the best interest of the patient:

> I would say on the unit there are times where there are people who no longer can communicate in any way, shape or form and have advanced care directives that at times family will say, 'no we don't want to do that anymore,' and will change their mind quite suddenly when the person is starting to deteriorate. So, we have sort of this set agreed upon care plan, and then sometimes it's changed. And I would say there are times where there are patients on the unit who have a few family members who come in to visit very infrequently but continue to pursue very aggressive treatment, and I found that was really distressing for me and that we were the ones enacting the treatment. We were the ones giving the care. Nurses would come to me and say, 'this patient is grimacing every time I wash them,' or 'they need more pain medication,' or 'I feel like I'm hurting this person when I'm providing care to them.' The family would still want to pursue and pursue and pursue, and then they wouldn't come see the person. And I think that was the part that I really struggled with. Is that you're asking us to do all of these extraordinary measures to keep your loved one alive. And we're here every day caring for them. But then we're not seeing the person at the top that's kind of making these requests.

The distress Sarah articulates here is that of one having to follow orders from above. Frontline HCPs often use the language of war or battle in their daily work, and this was especially prevalent during the pandemic, with phrases such as, "in the trenches" frequently heard. These morally distressing events have been shown to share stronger associations with guilt and shame than danger-based traumas for combat veterans.[259] Thus it is interesting to note what Sarah shares when asked how these experiences feel:

> Don't know, it's hard to pin on that one. I feel like in some ways I felt a lot of guilt and shame about it and that we're all like, I feel like a lot of frontline staff felt stuck in those cases. Like we have to do what the family says. We have to honor their wishes. You know, everyone has a right to healthcare. But to what extent is, are we starting to do harm? So, I'd say I felt guilty and maybe some instances of shame where I wish I had just stepped in and not been more assertive with family, but maybe just tried to understand their perspective a little bit more.

The More Beds, Better Care Act 2022 (Bill 7) has caused significant moral distress, particularly to social workers, with patient and advocacy groups voicing concerns that the Act violates fundamental ethical principles upheld in clinical practice.[260] The Act is

presently undergoing a charter challenge.[261] Sarah's interview took place prior to her being aware that the Act could possibly be declared unconstitutional.

> It certainly is (generating a lot of moral distress). I was actually just talking to a family about that before I came up here in terms of how they want to relocate their loved one. So, what are my thoughts on Bill 7 or the Act itself? I understand, the intellectual part of my brain understands, that we need to steward hospital beds. That they are a finite resource, that if a patient is ALC (awaiting long-term care) and their needs can be met in the long-term care facility, that's fine. And they should be moving to a long-term care facility. Where I find it challenging is the scope of the Bill and how broadly they feel that families can be relocated. So, I think it's up to 70 kilometres (In northern Ontario it is 150 kilometres). I don't feel that that's appropriate for patients who maybe have a life and a support network that are much closer to them than 70 kilometers away.
>
> Haven't seen it happen yet, but it's really scary that we can write that into legislature and expect vulnerable seniors to be moved away from their support network, family, community in an effort to steward hospital beds or steward hospital funds by moving some patients out. And I think if we look at it from a holistic perspective, if we're moving someone away from their support network to a long-term care facility further away, they may be right back in hospital without a support network again. You may not actually be doing anything productive. It feels inequitable. In some ways it feels reactive. It feels punitive to patients and families who are just trying to support loved ones in being in an environment where their care needs can be met. I would say inequitable in a lot of ways.

Sarah is then presented with a scenario of a couple who had lived together for 50 years, and one was being relocated to a nursing home which was a 120-kilometer round trip, with no local family. It would be interesting to follow-up with Sarah, if the Act is deemed illegal, to see how she would now feel:

> I personally have a very hard time with that. I would feel that that would challenge my ethics not only as a social worker and most definitely goes against the code of ethics that we adhere to as social workers, but my personal ethics. Yeah, in many ways it makes me feel angry. And it makes me feel upset each time I have to talk to patients and families about it, but I understand the rationale for it. Which makes it, makes it kind of ambiguous. Like I know there are folks here that would be better off in long-term care. And their care needs are appropriate for long-term care. In that instance where it would be the last time that a patient would see their spouse. Or it'd be too far away, I think there's always space for advocacy and I think that's something that social workers do quite well and something that I think is an important part of our job is that we advocate for people when they're not able to advocate for themselves or need

> assistance in doing so. I think if that were something that I were to experience on my caseload, something that I would push back against. Just in an effort to honor people's autonomy and honor their way or not their ways, but people are very resilient, and people have their supports and their networks that have made meaning for them in life. And have kept them alive and living up until this point. So, taking them away from those I don't think is actually doing our healthcare system any good. So, I think I would be very hard pressed in that situation to not advocate or not escalate the case further. Whether it be with home and community care or with hospital administration.

The issue of workload is a theme shared between all the HCPs in this study. From a social work perspective Sarah explains how workload negatively impacts the care that is able to be provided:

> There's been times where we've been short staffed, which is like the story of COVID. So, you have a caseload, like there was a time where I had a case load of 63 patients, on the unit I work on right now I have 22, so essentially tripled the amount of patients, who all had needs, who all had things that they needed done. And there were just not enough hours in a day and the expectation was that you just had to keep these patients, until we could hire more staff or get through the pandemic. Giving kind of like very base level care.

I ask Sarah what that felt like. Although she understands intellectually that this was a systemic issue and not personal, it likely didn't feel that way in the moment. Hence Sarah feeling overwhelmed at her inability to provide the care that she wanted to and believed her patients needed:

> I think in the moment I felt very overwhelmed. Like I would come in and be what are my priorities today? Looking back on it, I felt like I was just surviving. I was just trying to give what I could to as many people as I could in a day and knowing that it was a systemic issue as opposed to. Not me. Not being able to respond to 63 people's needs in a week. During COVID we were short staffed significantly, whether it was allied health, whether it was nursing, we were short staffed. A lot of times there were days where I was dressing, feeding, helping get patients ready for the day because that's just what we needed to do in those moments.

Sarah is asked if she has witnessed poor communication affecting patient care. Like a significant number of her colleagues in this study, she highlights the impact that just one member of the multidisciplinary team may have on many others:

> This all harkens back to a time where we had a new doctor on the unit, and I think there's a certain standard of orientation that staff get when they are

> brought into hospital, but doctors are contractors at the hospital. So, I don't believe they do the same level of orientation that we do. So, there was times where this person was writing orders or writing case notes and wasn't putting it in the right spot in the patient's electronic medical record (EMR). And then was saying that allied health wasn't charting things but didn't know where to actually look for our notes. So, we were making recommendations, and they weren't being seen by the doctor. The doctor was telling us things that were being handwritten into the EMR that no one knew were there, and then it resulted in I would say families having been given information that maybe doesn't accurately describe the programs and services that we offer, and staff having to replicate or duplicate things that they've done because it's been done. But then Doc said something else, and they have to go back and do it again. I know for social workers when we onboard new staff, they're orienting for about a month, shadowing, doing EMR training, and for docs it seems like they just kind of appear. And if they know how to work the EMR, great. But there's no sort of general orientation to like you're in complex care, what does complex care do. You're not in acute care. They're not at the rehab center, this is different. This is a different program in a different service… staffing wise at times it was just all hands-on deck. And we were just trying to get through what we needed to do in a day. It felt like just doing what needed to be done, like it felt like, okay, we don't have, we don't have a PCA today or we don't have a nurse today. So, you're going to feed someone breakfast. And you're going to help. It just kind of felt like piece meal. But it felt like we were doing what needed to be done to make sure that our patients were safe each day.

We now move on to discuss behavioural issues. It is fascinating to hear the testimony of other HCPs, not only nurses, who deal with the behavioural problems of patients and families. Sarah shares the experience of a social worker when caring for both families and patients in these situations. She eloquently details the emotional drain and exhaustion this can have on the HCP:

> I would say for both, when you have a patient that you know is going to be verbally abusive or possibly throw things at you or reach out at you, you're scared. You can go in very calm, but they can often read the energy in the room that you feel scared. When it comes to family members I feel as I progress in my career, I become more steady in being able to say, 'I won't be able to continue this conversation with you if you speak to me, with that tone. And I can appreciate what you're saying is really important but I'm going to be taking a step away.' But I do think that it compromises communication when you're feeling frightened of the person that you're communicating with. I know for a significant amount of time I had a patient on another floor who was quite verbally abusive and quite misogynistic and quite racist, and I had a very hard time even just being in space with that patient and I would find myself leaving and feeling exhausted. Being around that person and hearing the hate that they would spew was physically exhausting. But it was also part of my job, and you

> know, I'm a proponent of health equity. I believe everyone should have access to their social worker if they need to in hospital. So, I would go, but I would feel exhausted after spending time with this person.

When prompted to expand on what this feels like, Sarah shares:

> Conflicted, because if someone had spoken to me like that in my personal life I would have handled things quite differently, and in that situation you have to, you're there to complete a task with someone. Or you know you have to have something done by a certain amount of time in order to get equipment for their discharge or whatever it may be. So, you have to give them the level of professionalism that may extend beyond sort of the grace or values that you would extend maybe to people in your personal life.

Why do HCPs tolerate this abuse as "just part of the job?" Perhaps it stems from a sense of duty and necessity, similar to the words and behaviour a parent may tolerate from their teenager. Physicians are now pressing for increased penalties and consequences for patients who attack HCPs with the Canadian Medical Association lobbying the federal government for definite protections for HCPs, similar to the penalties for assaults on police officers.[262] I press Sarah as to whether any other emotions come up:

> Definitely afraid. Just like a real sense of uneasiness like I know for this one patient, I'd go into his room, and I would feel my, like a full body reaction. Like my hands would get sweaty. It was a real like you want to say anxiety response, because I don't know if they made me anxious. More so, just afraid and really just upset. Like what they would say is upsetting. It doesn't align with who I am, this person. We got to a place where if you were going to say anything crude or rude or racist, or whatever it was, I'm going to leave your room and you can continue to yell, but I'm not going to stay here. So really firm boundaries. But it really conflicted with who I am as a person and what I believe, to spend time in space with that person, and even just give them the energy of someone listening to that.

4.5.1.3. Healing from & Dealing with Moral Distress

Circling back to the situation with the new doctor and the patient and family receiving false hope, Sarah expands on how that situation could have been handled better. She highlights the importance of the consistency and experience needed at management level. Regarding this particular situation, it is interesting that many of the HCPs on the

unit were experiencing moral distress in isolation. This speaks to the importance of a multidisciplinary approach when dealing with these issues:

> I think from a frontline perspective, we were pretty clear in that we felt that our boundaries as professionals were being pushed. But I think at that time, the unit was going through a lot of change. We had just switched managers. There's a lot happening. So, I think everyone was collectively just trying to survive essentially, and then once it was really, the team, sort of collectivized, and we brought it to the attention of the clinical manager and of the medical director. Things were taken a bit more seriously. And I wish maybe we had come together collectively sooner to say something, because I think everyone was kind of experiencing the same thing in the silo. And thinking, 'oh, it must be a me thing,' and then once we all actually talked about it everyone was experiencing the same thing, just in their sort of own professional silo. I think that would have been helpful.

How would Sarah handle situations differently where families are pushing for treatments Sarah believes are futile or harmful to the patient:

> In these instances, I think care directives need to be reviewed far more frequently than they are. I find patients will come to the vent unit, we'll set them as a full resuscitation or a send to acute care and then we just kind of leave it there. Because I think like every, I don't know what would be an appropriate amount of time to determine, every couple of months we're revisiting people's code statuses. How have they changed? What is our plan? If they start to deteriorate and being more proactive as opposed to reactive. Making sure that families are a part of those conversations.

I suggest to Sarah that something could be flagged and added to the multidisciplinary team rounds:

> Absolutely, yeah. I found there would be times where someone would be deteriorating. And we'd be like, 'oh, what is their code status?' And we would have to be sort of responding from there. Whereas if we were constantly looking. You know this person's had a decline, this person is doing well, this person's stable. We could be assessing what someone's code status is and if it's appropriate given their current prognosis.

Prior to this research the author had developed recommendations for improving advanced care planning on the long-term ventilation unit.[263] Many of the patients on a long-term ventilation unit are suffering from progressive neurological degenerative diseases like ALS and at some point, prior to death, surrogate decision making for end-of-life treatment is required. Though only a minority of patients with ALS will be admitted

to a long-term ventilation unit for mechanical ventilation following tracheostomy, such interventions commonly occur under emergency conditions, without advance directives or clear advance care planning. We know when patients with ALS have not shared their choices for future care, what often results are unwanted treatments, and moral distress for those who must make healthcare decisions when already feeling afraid and overwhelmed.

Though patients most frequently count on their families and doctors to speak on their behalf during a crisis, studies have shown that neither are able to accurately predict a patient's wishes for life-sustaining treatments.[264] This fact alone underlies the importance of advance care planning taking place as early as possible, and ensuring an ongoing conversation, at a minimum whenever there is a change in the patient's condition. However, as anyone who has worked in healthcare long enough can testify, it is not writing a good policy that is difficult, it is getting the policy adopted consistently, and sustaining it in practice.[265]

Referring back to implementing the More Beds, Better Care Act, Sarah is asked how she would deal with the situation of the patient being forced to move to a nursing home not of their choosing. What would she do if she felt her personal line in the sand had been crossed:

> So, I find I do feel very supported by clinical managers in the hospital. I find they're kind of stuck in-between with us, they're not directors, they're not the powers that be, they're also not frontline staff. So, I would start by having a conversation with my clinical manager about where I feel that ethically one could go against my personal ethics. But two, professionally as a social worker what is barring me from enacting the code of ethics that I adhere to. And I think there are times where if that's, if the hospital wants to tow this line of, okay, you're going to move to wherever county, 70 kilometers away from your loved ones, then hospital administration can step in to tow that line. I feel like there is a place where if my professional code of ethics or my professional duties I can't enact, then I feel there are spaces where I would feel okay stepping out and providing advocacy and support to the patient in possibly processing some of the feelings around moving very far away, but I don't foresee myself supporting the hospital in moving that person there. That's an administrative and bed flow thing, then that's something that they can process.

Sarah is asked when looking back at some situations where she has experienced moral distress, what did she find helpful in dealing with them, coping with them, and healing

from them. Once again, the vital importance of peer-to-peer support is emphasized by an HCP:

> I would say the team on the vent unit is one of the best teams in the hospital. And I would say working with the team, talking to the team, talking with the team about what's happening has always been really helpful, and I think even now, I still have strong relationships with the folks that are up here. Just because sometimes they need to debrief. I find it's much easier for me to debrief with them now that I'm not up here than it was when I was working on the unit. But I would think having coworkers or colleagues that have walked the same path and being able to talk to them is one of the most supportive things that we can offer.

It is noteworthy that Sarah shared it is sometimes easier, and likely more beneficial, to listen and be present for another HCP when you are not also trapped in the same suffering. You are then able to be somewhat more objective. Though perhaps not walking the same path right now, Sarah shares that it is necessary to have walked a similar path if the HCP hopes to provide effective peer-to-peer support. “Peer-to-peer support, yeah. It's one thing to have another listening ear in the hospital, but until you… until you've actually worked it, it's hard to kind of conceptualize maybe some of the things that happened on the vent unit.” I share with her that this was actually the catalyst for this research; how I was listening to two nurses in the midst of the pandemic as they expressed their suffering, and I realized that they were traumatized. One of the nurses in particular explained how she had tried speaking to a mental health professional but felt they didn’t understand the particularity of hospital-based moral suffering. i.e. there was no identification. Previously discussed in Chapter One was the essentialness of identification to the healing found in 12 Step spirituality, the importance of a shared experiential knowledge. Sarah goes on to say… “specifically like the chronic vent program. Like it's so unique it comes with so many ethical quandaries that it's a really unique place. And I think being able to talk to other people… it can be really supportive to have someone that's done the same job and has worked with the same patient population.” She further explains that… “I would say that's one of the, if not the only thing, that I found has been really helpful. And taking some time away. Like good, substantial periods of time away. Like two weeks at a time definitely can be helpful.”

Sarah is asked if she has been required to care for patients who she may not have felt qualified to care for. Like other HCPs in the study, she articulates the benefits of and need for mental health supports in the hospital:

> So, we'd see this comes more so from the mental health scope of practice, I'd say hospital wide, we need to do more to support people's, patient's mental health in this facility. There were times where I felt that I could have done more to support mental health but felt that I didn't have adequate clinical supervision to do so. So, I think there are interventions or even just therapeutic approaches that patients would benefit from on the vent unit. Looking at dialectical behavioural therapy or cognitive behavioural therapy as supportive methods to help people that are going to live here in perpetuity, there is no discharge disposition, but there's no clinical supervision and there's no sort of mental health team or emphasis hospital wide that makes it so those types of therapies or supports can be enacted.

She is then asked if she had a magic wand and unlimited budget what that could look like:

> I think starting with having a psychologist or psychiatrist more readily available would be very helpful. I think because the primary patient population here is geriatric, whereas on the vent unit there's a significant well, not a significant, but a greater number of young people on the unit, having a psychiatrist that's not a geriatric psychiatrist would be helpful. And then looking at a mental health team where social workers, occupational therapists, are able to provide psychotherapy and have clinical supervision. Because we have the resources in-house social workers, occupational therapists, I believe even nurses can register as a psychotherapist in the province of Ontario given they have the right training, and if there was a team put in place and if there was clinical supervision and adequate training, I think we could actually be supporting the mental health patients in the hospital better than we are now… I think families, at least for the vent unit, would benefit a great deal from some type of caregiver support.

Sarah has provided some wise and evidence informed recommendations.[266] Moving on to the pandemic I ask Sarah if she and her colleagues have had enough time to reflect on what was faced by the healthcare team. "I don't think so. I think we're all kind of just coming out of it now. No, I don't think we have, and I don't know if we will, because in healthcare, the beat just kind of goes on… I think for myself, I look back and I think, wow, that was really crazy and then I just keep going on with my day." I share personally how someone may mention something that I had completely forgotten happened during the pandemic and I'll have a visceral reaction. Sarah emphatically

identifies. “Absolutely! I don't know if that's a trauma response or what it is… It's not at the forefront of my mind. It's not something that I'm actively reflecting on.” I ask her how she feels today about the pandemic:

> Looking back, I can say, I would say that my mental health was quite poor during COVID. But I didn't realize that it was. I think we were so just in the thick of it. Just trying to go through the motions each day and making sure that patient care is being met. But now that I look back, I can say I wasn't doing any of the things that I would usually do to take care of myself. I was tired. Was definitely irritable with my loved ones at home. So, looking back on it, I know it was a distinctly hard time in my life. But I don't feel that now it's something that I continue to carry with me, and I don't know what's changed or how that changed or when. Maybe just because I changed jobs too, that that's helped me kind of separate. Like that was the COVID part of my career and now I'm in a different part of my career.

Sarah’s testimony would appear to confirm that moral distress (though not moral injury) can dissipate, and the HCP suffer no lasting sequelae, when they leave the morally distressing workplace, or the external drivers of the moral distress end. I relate to Sarah that my life was also completely unbalanced during the pandemic. I ask Sarah if there was another pandemic similar to COVID next week, what would she do differently:

> Would I do differently? Can I do differently? That's an interesting question. So, I'd love to say that I would keep all the good habits that I have now that we're out of COVID, but I don't know if I would. I don't know if that was just me coping at the time. I think I would spend more intentional time speaking with my coworkers and debriefing with my coworkers because I think that was some of the most valuable things that we were able to do. To kind of survive the last two years. So, I'd love to say, yeah, I would continue to eat healthy and spend time outside and then workout and do all the things you know are good for my mental health, but I don't know if I would. If we were right back in the thick of it. I might just go right back into survival mode and hope for the best.

Sarah is asked if she has ever left or considered leaving a position due to moral distress:

> Sure. So, I did leave the vent unit. Just I've come to a place where I had acknowledged that my mental health had been impacted just by the number of, significant number of patient losses that we had throughout COVID. Through experiencing this instance where this new doctor had been onboarded and maybe just wasn't a good fit for the team and wasn't a good fit for the patient population. And felt that if I were to continue in health care, which is a job that I actually really enjoy, I enjoy working on an interdisciplinary team, enjoy working

> at this hospital, I needed to switch the patient population that I was working on, to something that felt a bit more hopeful than working on the chronic vent unit. The piece that I think really stuck with me is the young people that live on the vent unit, who will live here for a number of more years and how I feel that the unit oftentimes gets under resourced in the hospital. And I think now it's quite poignant how you can visually see the differences between the vent unit and the new palliative care unit. And where we invest our time and energy, is it in the people that are permanent residents? That are going to live with us for the next however many years? And they don't have access to the same resources. There's no therapeutic recreation. There are limited respiratory therapy resources. Which means that patients that don't have vent trained families and can't be coming on and off the unit as they would like to see fit. So, I think that was the hardest piece for me was seeing the amount of young people who were for lack of a better word, stuck on the vent unit with very little options for freedom or autonomy in their lives. And there's some really great smart, creative, wonderful young people on that unit, that if our healthcare system worked differently, could be at work. Could be out in the community doing different things and enjoying their life a bit more. But the way our healthcare system is set up and the way that the amount of resources it takes to support a person on a vent, this congregate living situation is really all that we can offer.

I explain to Sarah that moral distress can often be cumulative. In the literature, the term moral residue is sometimes used to signify a buildup of moral distress over time. There may also be a specific moral injury, from a traumatic event, where we feel wounded. If she had to think of one event what would come to mind when she thinks of moral distress, what might that be:

> When I think moral distress? I would say for more me it's more the moral injury. It's like one little thing after another. But I would say Christmas time of 2020 – 2021. I want to say there was an instance where we had three middle-aged women, all with bulbar type ALS who were admitted at the same time and they all passed within a couple weeks of each other. And as the first one passed, we said we need to have an order set in place so that you know there's sedation and pain management and stuff for their secretions and oxygen ready to go. And by the third we still hadn't done that, and I felt that some of these women were suffering, and I felt that we hadn't done enough to support them in their passing.

When you go home at the end of a shift like that, what does that feel like for Sarah:

> It's quite devastating, I think. To just… To seeing, just seeing how a care team can say okay, we have a solution to this problem and then you know it happens again, and it happens again and the same solution hasn't been put into place. It felt kind of devaluing as a care team. Not even just me as a professional. But it felt, it felt devastating, like it felt, really sad. The mood on the unit was really

> low, like everyone was distressed. Nurses, docs, RTs, yeah. I think it was just the sequence too. Like it was so it was a couple of deaths in a row and none of them were good deaths.

I share with Sarah how professionally and personally it was a tough time for me. My mum was dying in England at that time, late 2020. I went home to spend a week with her, and I felt so guilty leaving work and taking time off. Also, guilty flying because there was a lot of travel shaming going on at that time. It was frankly a horrible time, but I followed my Heart. I could have received many different opinions of what I ought to have done in that situation, but I followed what I call my Heart. I ask Sarah what she calls that place inside herself where you know right from wrong; that guides you:

> Yeah, I think heart would be appropriate or intuition. I feel I always kind of have a good sense of what I feel is right and what I feel is wrong. May lead me to troublesome places at times where I'm having to speak to my manager about things that I've seen or, you know, speak to the clinical manager or whoever it may be, but I do think that it's an important piece and I would say for people on the vent unit, some of them have no one. So, they need an advocate.

Where does Sarah find that moral courage:

> I don't know. Maybe just from having a big mouth, I don't know. I feel sometimes I'll see things that I just, just feel unjust. Maybe that's why I feel so upset about this palliative care unit renovation and not doing the other side of the unit, but there are times where I just feel. I think equity is something that I value across my life and when I see people that need more assistance or have a right of access to more assistance to be able to do things that we know that they're capable of that aren't given those opportunities, I find that to be really frustrating.

What advice would Sarah give to a colleague for dealing with moral distress:

> I think reaching out to your other colleagues is probably one of the most valuable things that you can do. Yeah, because people that may seem like they are not affected by things probably are and I think having space for peer support or even just pure conversation is where a valuable sense of validation can come from. Or even just solace, empathy, collectiveness. And so, I think that would be my takeaway? Yeah.

Sarah is asked for her top three ideas as to how things might be improved at an organizational level:

> Top three, okay. Hard to pick three. Okay, I would say more of an emphasis on patient and family mental health. Proactive means to supporting behaviours because mental health behaviours are often born out of mental health, so holistic approach to mental health. Or even just some more mental health supports in the hospital I think would be helpful. It's tough. I'm stuck now… So definitely the first one, yeah, definitely mental health service provision is lacking in the hospital. I would say patient centered care and say a lot of the time we're told to work on a home first discharge. Yeah, we've been told that a lot lately. Work on a home first discharge, but what I really think we should be looking at is patient centered care. And what is our patient and family directing? How do we center them in care? In terms of care trajectory, if they're going to long-term care, if they're going to retirement home, to community. How are they at the center of their care and helping to determine their care pathway as opposed to you're not progressing in rehab, so you're going to go to the transitional unit, then we're going to have you wait for long-term care, but you're not actually going to get to choose, you're going to go to a low wait list home and then you're on your way. So, I think maybe less of an emphasis. I find sometimes as social workers were kind of like glorified bouncers at the hospital. Like oh, you know your time is up. It's time to go. Where are you going to go? Okay, you've got 30 days to find your retirement home. Let's go. And I think if we centered our patients more in their care and had more active conversations where patients were or patients or families or SDMs were able to self determine, I think we may be looking at a more proactive way of discharge planning and getting people out of the hospital as opposed to pushing home first, a strategy where there aren't very many resources in the community to be sending people home to begin with.

Sarah's story shines a much-needed light onto the moral distress faced by social workers caring for patients on a long-term ventilation unit. There are distinct and explicit features seen within social work, including working with vulnerable individuals and communities needing high levels of resources, with these relationships either facilitated or hindered by an organizational environment such as a long-term ventilation unit.[267] Sarah's testimony highlights how the long-term ventilation unit, particularly during the pandemic, may be affected by management decisions that present a threat to the relational ethos fundamental to social work practice.[268] Sarah clearly reveals that as a HCP she wrestles with the impositions of limited resources and lack of autonomy sometimes felt by the social worker. Thus, it is challenging for Sarah to undertake her work in accordance with the values and practices of her profession. Her testimony highlights her struggle to uphold her professional and personal moral codes, and her limited moral autonomy caused by constraints imposed by her diminished ability to influence organizational resource utilisation.[267]

Therefore, it is unsurprising for Sarah that these situations resulted in a high level of work-related moral distress and its classic sequelae, including shame, guilt, fear, and anger. Importantly Sarah is aware of and articulates some of what is needed to deal with the causes and conditions inherent in the development of moral distress in HCPs. Namely peer-to-peer support, mental health support for patients and their families, and strong personal support networks outside of the hospital. Ultimately, to protect herself and heal, Sarah moved to another patient care area.

4.6. Medicine

The physician's role in contemporary Canadian healthcare carries specific professional expectations making it somewhat distinctive when compared to other roles. These areas of responsibility may be defined on several fronts including, individual, societal, logistical, and legal.[26] In the long-term ventilation unit a physician may experience moral distress in matters related to – caring for the critically ill, dealing with challenging families, conflict with senior leadership, issues with accessing specific services and resources, medico-legal problems, disagreements within the multidisciplinary treatment team, and regulatory college constraints, amongst others. These conflicts may cause physicians to feel that their professional and personal integrity is compromised, leading to job dissatisfaction, negative self-image, burnout and considerations of job abandonment.[269]

Over the past few decades nursing literature has comprehensively studied moral distress, while medical literature has mainly focused on the closely related issue of burnout.[270] Recently however we have seen an increase in medical research looking at the interrelatedness of these two concepts and the experiences of physicians.[269] It has been shown that during the pandemic in Canada there were significantly higher levels of moral distress, emotional distress, anxiety and depression, and increased rates of diagnosed mental disorders in physicians and other HCPs.[30] The following story covers Jean-Luc's long career as a physician treating patients on the long-term ventilation unit.

4.6.1. Jean-Luc Picard – Physician

Dr. Picard has significant experience as a physician caring for patients requiring long-term ventilation.

4.6.1.1. Meaning & Faith (Resilience)

When asked what led to his working in healthcare Jean-Luc recounts that as a child the medical world was a big part of life in his family. Many of his relatives are physicians or other HCPs.

Hospital patients have become more complex, and for HCPs taking care of a patient today it is far more complicated than it was only 10 years ago.[271] This is true on the long-term ventilation unit and especially since the pandemic. Jean-Luc describes how 10 – 15 years ago… “patients were primarily neurodegenerative or massive post neurologic event. And they were essentially persistent, non-communicative vegetative state and on a chronic ventilator because these were the decisions that the families had made.” However, this is no longer the case as Jean-Luc details:

> One of my chronic vent patients sat on our peer review committee this year handing out the grants for research for the physician group. Another group of my patients have a communal video game group where they game remotely from their rooms together on multiplayer platforms. Another one of my vent patients holds a monthly poker game with outside people that I attend, and the clinical managers attended. This is a very different population than a decade ago when they were all persistently non-communicative in the bed.

Dr. Picard offers an enlightening definition of his personal understanding of what moral distress is. He is able to pragmatically articulate the concept down to the level of bedside care. His use of a triad involving the patient, the family, and the medical system, is very powerful:

> If I'm trying to understand the concept of moral distress. I think it's when you are unable to do something you can do, or you're prevented from doing something that you can do to help, or you're unable to do something that you can do to help. Or there is a clash of some sort in the health care process. I'm going to say, when I look at how patients are cared for, I talk about a triad… what the patient wants, what the family wants, and what the medical system is able to offer. When those three are aligned, you have no issue. Medical system is able to offer what the patient wants and what the family wants, we're all good. When

> one of those is out of alignment there is a conflict. I don't know if that leads to moral distress, but there probably has to be a misalignment for there to be the potential for moral distress.

I say to Dr. Picard that his conceptualization is as well as I have heard moral distress explained. I offer the succinct definition that it could be when I think I know what the right thing to do is but I'm unable to do it.[24] He brings up a very important point here when he answers. “And there's a difference between I'm unable to do it because it's not doable. That for me doesn't cause moral distress. If I'm unable to do it and it is doable, that's a problem.” In hindsight I regret not asking Jean-Luc to further expand on this point and provide some examples. I believe what he is referring to here is, in 12 Step spirituality, the healthy acceptance of one’s powerlessness in a specific situation. The serenity to accept the things I cannot change.[224]

I ask Jean-Luc if he considers himself a religious or spiritual person and what that might look like in his life:

> Yes, I grew up in a Hindu household, so my understanding of a religious framework on the world is from the lens of a Hindu faith. I think as I grow, that really just means to me that there is a set of expected behaviours that lead you on the good side of things. And there's a set of behaviours that we do on the bad side of things. And the more we tend to on the good side overall, the better it seems to be. On a very specific basis, you know, I believe in reincarnation. So, the whole idea of death doesn't particularly bother me in any way. It's a cycle, which is not true for everybody.

When asked if his religious worldview is helpful when dealing with difficulties Jean-Luc answers very confidently and with great faith that… “100%. Absolutely does. Yes.” In relation to this Jean-Luc is then asked if he had a new medical student or a resident working with him, what advice would he give them for dealing with moral distress:

> I think that moral distress gets amplified if you are unable to separate, or silo, or understand what your role is. This is actually, again, part of the religious view. There are several different ways in the Hindu culture to enlightenment. And one of them is following your duty. So, your duty is done without expectation of outcome. It's a very important concept that we're taught very young in the Hindu religion. So, it doesn't matter what happens if you did what you were supposed to do. So, if I've done everything I can do at the bedside with the family, with the patient in the communication, I am disinterested in the outcome. I should only be interested in what my duty in the process is and getting there.

Beautiful words. From the wisdom of 12 Step spirituality, shared in the rooms of AA, one may hear a similar sentiment expressed as… “You may plan the event but not the outcome, that’s in God’s hands.” Jean-Luc adds… “Let go the outcome and ensure that you did what you should have done in the process.” I share here how a similar mantra helped me greatly during COVID, especially when we were trying to roll out the vaccines… “I'm going to do what I can, and the outcome is in God's hands.” Jean-Luc agrees and adds. “That's right. And so, I think if I was to give anybody any advice, if they're starting, it would be that. Make sure you're doing everything you're supposed to do. Then you leave it at that… and then go have a Guinness.” 12 Step non-consequentialist spirituality (minus the Guinness) would align with Jean-Luc’s deontological philosophy, in contrast to utilitarianism which is predicated on the idea that the morality of an action is based on its consequences.

Interested in Jean-Luc’s thoughts on the association between burnout and moral distress in medicine[272] I ask him what he thinks are the primary driving factors for burnout in physicians:

> For me, it's too much work and not enough time. And it doesn't matter how much time you give; you don't have enough time. And it's..’. It’s relentless. Yeah. I think that's a big one. And that's another one where it's hard to get to the I've done everything I can do, and the outcome will be what it will be. So, today I was in my addictions’ office right before I came here. Most of my addictions’ patients have been on the same dose of drugs, there's no change and everything's stable. Every now and again, there are people that need long conversations. So, I probably went through about 80 patients today before I came here to do this. And of those, two patients took almost an hour and a half total of the day. And that is because they just had issues that we needed to talk about and go through. But I'm very aware that I'm running out of time to do the work I need to do. But I've always said from day one, it's every patient that's in front of me gets the time they need, and we'll work on the rest of them from there. But that makes me short. And in fact, I was on the phone with one patient, and my general patients are very used to being very quick. ‘Hi Dr. Picard, no change in my medication, everything's good, no side effects, see you next week.’ That's the bulk of the interactions when prescribing high dose narcotics. I was on the phone for over half an hour with one patient, and the other patient was sitting outside the office waiting. And I hear them cursing and swearing. And I put the phone on hold, and I said, ‘you need to stop that right now. I give you the time you need. I'm getting this patient the time they need.’ Turns out he was cursing and swearing at his phone, not at me, and not at the wait. But the point is, is you got a little bit short, and you got a little bit of

> whatnot. And the fundamental driver of that is not enough time and too much work.

This issue of too much work today in healthcare is driven in large part by the increased complexity of patients, as discussed earlier in this section. It has been said that much of this complexity stems from a culturally created sick-care system, which essentially performs damage control, whilst reactively managing sickness and the results of poor lifestyle choices.[273] I posit to Jean Luc that this is unsustainable; that we cannot keep building hospitals and hiring more staff, we have to go back to the root causes. I ask him how we might do this:

> All right. Listen, nobody's going to like the answer because it's tied to everything that we do. There are too many people on this planet. This planet, as it is right now, 8 billion people, does not have the capacity to absorb the economic activity and expectations of those 8 billion people. We have too many people wanting too much. So eventually there will be a feedback loop, and that population will be affected because there will be not enough... cool weather, not enough water, not enough food, not enough healthcare, not enough whatever to sustain that population. That's the big picture analysis that I've come to. I might be right. I might be wrong. But seems to me that if we're worried about climate change, economic impact, the impact of economic activity on the planet, diminishing resources, increasing demand, the fundamental driver is too many people.

Some may disagree with Jean-Luc's population analysis. Many believe that population collapse due to low birth rates is a much bigger risk to civilization than global warming.[274] I ask Jean-Luc what health advice he would give to his children. "Eat less. Be a little bit hungry all the time. Move more. Do not sit and be sedentary and put some balance… I think there probably does need to be a balance to maintain health. So, eat less, move more. Put a balance in your life." I reply that if Canadians did this his workload would reduce by about 70%. Yes, he replies… "It's a fact! That's an absolute fact! Absolutely it would. But it doesn't. And it won't. You know, it's the simplest things that are the hardest to do sometimes." Too true. Like applying 12 Step principles to one's daily life – simple but not easy.[7]

4.6.1.2. Moral Distress in Relation to - & Emotions

It is fascinating to hear a physician, who was working on a long-term ventilation unit during a respiratory pandemic, share their personal and professional experiences and insights regarding our pandemic response and its relationship to moral distress:

> So, I think as you experienced the pandemic and the lockdowns and the uncertainty, it was a bit of chaos and a fair bit of chaos. Then it started to solidify in how things were going. And they were primarily IPAC (Infection Prevention & Control) driven with a sense of really locking down, limiting the spread, isolating, doing what you could do to prevent the spread of COVID-19. With that came an unavoidable side effect that people didn't get the therapy and care they need. Not quite so much on the vent floor, but somewhat on the vent floor. Very much so on the rehabilitation side and I could speak to that because I was part of the Medical Advisory Committee (MAC) when we were discussing this. The best example I can give is in the initial part everybody did, this is it, this is how we do it, this is how we do it. A year in, you can see you're not meeting the patient's needs, but you're still kind of okay, this is what we've gotta do, I'm for it. 18 months in, we've actually got a problem now because now people have realised our vaccinations have spread. Many people are protected. This is not killing the people we thought, the initial projections, the population of the planet was going to be decimated and that didn't happen. And so, from there, we got to a reality. If you're on a high intensity rehab program and you have 30 days and you have an exposure to COVID-19, you were isolated for ten days. You missed a third of your therapy. You didn't get an extra ten days, you had 30, you missed ten. Got a second exposure, you missed 20. People weren't getting bathed, things weren't happening. And so, as the Medical Advisory Committee, we kind of put the question to the infectious control people, ‘why are we open? Why are we even doing any business if we can't do our business, just stop.’ And then I think slowly, the Medical Advisory Committee found its footing and said, you know what, we're actually in charge of this. Not IPAC. We're not doing that anymore. We will take your advice. We will listen to it diligently and carefully, and we're going to make a decision on the balance of probability and risk of what we're going to do because we're trying to get somewhere with therapy. And absolutely limiting and mitigating the risk means we're not getting anywhere with therapy. That really essentially sums up where we got through over the few years. And as a group and as the Medical Advisory Committee kind of said, okay, enough with the zero risk, we will manage risk, we're going to manage it giving the therapy we need to give.

This testimony powerfully highlights the chaos and uncertainty of those first 18 months of the pandemic. Even though we were told the policies being implemented were evidence based we now know that many of them were actually fear based.[275] The devasting economic consequences of these ill-informed policies, such as extended

lockdowns, will be felt globally for years to come.[276] The profound negative effects on human health and well-being is still being understood and calculated. All over the world the excess death rate, not from COVID-19 infection, but possibly due to our flawed pandemic policies, continues to be seen and felt.[205]

Listening to Dr. Picard's testimony reveals a significant driver of moral distress he experienced during those first 18 months of the pandemic. Studies have highlighted a positive relationship between HCP moral distress and professional autonomy.[277] What Jean-Luc experienced was the profound loss of his professional autonomy as a physician. It is clear to hear in his voice the frustration felt at the loss of control normally held by the Medical Advisory Committee, as IPAC took charge. Furthermore, the frustration at himself and his colleagues for allowing this to go on for too long is clearly articulated. Medicine, of all the various health professions, likely enjoys the greatest autonomy in Canadian healthcare. This is due in no small part to the obvious, and clinically necessary, hierarchy in hospital-based healthcare, and the fact that physicians are not usually employees of the hospital. This was likely the greatest loss of autonomy that will be experienced during Jean-Luc's career. I ask him what we can learn from how we handled the pandemic, and he goes on to share:

> I think like most policies... and I think that this is a fundamental, systemic issue the way systems are created. And it's a little bit, little bit different for many physicians. So, when I determine a course of therapy or when I write a particular order or when I make a diagnosis or when I whatever we insert, whatever it is I do there, I wear that responsibility, that's mine. Nobody can come by and say it wasn't Dr. Picard's problem or fault or whatnot. He did the examination, did the investigations, came to a conclusion and ordered the therapy. There's no room in there for any other responsibility. The reason I preface that is that means that I'm on a daily basis very acutely aware of the risks I'm balancing and the risks I'm taking when I make a decision. I think systemically we are completely risk averse and nobody wants to take a chance, put themselves at risk, put their neck on the line or any of it. So, the answer is always towards zero risk in any systemic situation. The next part that maybe is important is 26 years in the armed forces is also a measurement of risk and benefit. You can't be in the armed forces and not take risks. The entire business is managing risk. So again, back to the systemic pieces. When you're looking at bureaucratic systems that are sitting in office buildings, the tendency is to use zero risk, especially when they're making decisions that don't apply to their day-to-day reality. So, when you've got the National Council on Vaccine Effectiveness or whatever that group is, they're not actually delivering health care. They're not seeing what's happening. Part of my practice outside of this

> hospital is long-term care and long-term care was devastated. If we thought we had problems delivering therapy in high intensity rehab, we really put elder people in prison and locked the entire society down. So, I think the biggest policy failure was to actually examine and understand the risk. The moment that the bulk of the population was vaccinated, the majority of the risk was mitigated, and we didn't act like that.

Dr. Picard articulated that we put our elderly and most vulnerable “in prison,” during the pandemic. Without doubt there was an overall increase in risk aversion during the pandemic,[278] and it is now clear to many that the harms we did to those who had no voice, far outweighed any benefit to them or the wider society and that this was a significant cause of moral distress.

I ask Jean-Luc if families sometimes ask him not to let the patient know the diagnosis or prognosis. His answer is clear and refreshing:

> That's happened often, and I don't listen to that. Yeah, that is actually not permitted regardless of what the family want. Yes, they will have all kinds of reasons why, and I'm just quite frank and say, ‘I'm very sorry you're not my patient. That person is. And they're entitled to this information.’ I'm not... I don't entertain that restriction. But yes, that happens a lot more than you think it should.

I also ask about the growing burden of documentation in healthcare. I share how as a student nurse in the 1980’s I probably spent only 5% of my shift on documentation. Jean-Luc shares that… “during the pandemic, people were spending up to 50% of their time donning and doffing PPE. How are you going to be able to provide any care when you're putting on PPE and yanking off PPE? Yes, I agree this burden is growing.” I’m interested to know how the documentation burden has changed during Jean-Luc’s career. It is unusual and interesting to hear an HCP talk about the positive improvement in documentation:

> In the beginning the documentation, 5%, maybe even less. However, the flip side of that, that we don't always talk about, is the documentation was shit. So today, yes, maybe there is a bit more of a burden on us, but 100% my documentation is way better than it was, right? Like it was a scribble that wasn't particularly legible. I would go back and read it, and it wasn't clear what I wrote and what the hell was going on. Now in an electronic medical record (EMR) I can read my notes, I can follow what I'm thinking, other people can follow what I'm thinking. And it is a little better. In terms of the burden that we put on. Yes,

> it's probably leaning the wrong way. The best example I can give you firsthand is when our EMR first came and we were doing interdisciplinary team rounds; whoever designed the team rounds template. I was watching. We were in there and there must have been about 70 or 80 mouse clicks that needed to be done in tiny windows before we could start talking. This is ridiculous, that makes no sense whatsoever. So, part of it is the design of the model that we use of the platform, because not all platforms are equal, number one. Number two, as a receiver of medical documentation or a consultant sometimes when you look at what other EMRs regurgitate to you for patients coming in, it's almost useless, because it's too much shit. That it's not searchable or done in a way that is indexed appropriately. It's just there. And after you scroll through so much you go, 'I'm not looking at any more of this, it's just user fatigue and I'm not doing it.' Even though the information you need is buried in that. So, I'll make the comments on the platform and the way that's done, then I do not see the workflow analysis of end users being integrated into the platforms. When we looked at basic order sets in the EMR at another hospital for physicians, I can't speak to Allied health, MAC spent a ton of time allotting resources to physician groups to say, 'get together, run your workflows, your order sets need to augment your workflow, not interfere with it. If they interfere with it, send it back, do it again, redesign it, do what you need to do to get those things to make your workflow better.' I don't know that Allied Health has that same opportunity, so they end up with a product that's imposed upon them that then says you need to fit within this widget, and you go, 'but that's not how I work,' and they say, 'well, we don't care, this is how it works.' And so, I think that that's a pretty big problem. And I don't know the solution to that because at the end it sounds self-evident that we want technology to enable care, but that's not what we purchase or implement.

Jean-Luc is given the hypothetical scenario where the full might of Microsoft is offered for five years to develop solutions to the issues with healthcare documentation. How might that look:

> So, I think we're closer today than we ever were. And I think that a passive environmental generative artificial intelligence (AI) program will absolutely change the way that documentation is done. This is real in physicians' offices today. So, we're having a conversation yeah, it's doing the documentation. You can purchase that today. Ten years ago, or even five years ago that was a scribe. We're having a conversation, and I've hired somebody to do the documentation. In the height of the pandemic, and even now, today, I'm not sure that that isn't a good idea to have actual scribes on the floor doing the charting for the allied health professionals. If we have a shortage of nursing resources, we have a shortage of bedside care, then let the regulated health professionals do what they do and let somebody else do the writing. There are some limitations. I've suggested this in other settings to senior teams in administration. There's some requirement by the College of Nurses that you have to do your own documentation. You're not allowed to give it to anybody

> else. So that's a stupid regulation, right? It's very clear that somebody can write anything they want for me, and I'll put my signature at the bottom of it. It's as if I wrote it. I don't know why that's not the same for allied health. Maybe it is. If it's not, it should be. So, if you were to give me Microsoft, I would take the entirety of Generative AI to say, this is with me all the time, understand what I'm doing clinically and put it in the chart.

Unfortunately, the College of Nurses (CNO) documentation practice standard has not been updated since 2008[279] and the CNO still advise on their "Ask Practice" website that the… "documentation be completed by the individual who performed the action or observed the event, as it can blur accountability of who provided what care."[280] Jean-Luc is quite correct in that the use of scribes and/or AI is truly the way to significantly reduce the documentation burden for healthcare providers. It seems that Medicine is far ahead of nursing when it comes to the adoption of these technologies and practices, and it is time for the CNO to fully update their documentation standards in light of this new documentation paradigm. AI and/or scribes could significantly enhance the work-life balance of nurses and greatly lessen their administrative tasks.[281]

However, AI does not come free from issues or risk,[282] though Jean-Luc is quite clear in stating that the benefits of AI will outweigh the risks:

> So, people talk about the privacy that sort of thing. All of that's true for all of us, for how we interact, how we do this, where we do it. You have to be as aware of your privacy as the scribe, as the people. We all have to. So, yeah. Is it a risk? Absolutely. But this actually comes back to the conversation we were having about taking risk. So, there's a risk to not doing it. And we're going to run out of regulated health professional hours to deliver the care we want to do. Which one do you like?

In answer to Jean-Luc's rhetorical question, we need to take that risk. The use of AI, scribes, and advocating for the CNO to modernise their documentation practice guidelines form part of the recommendations in Chapter Five.

4.6.1.3. Dealing with & Healing from Moral Distress

How might Jean-Luc deal with a situation where the family is pushing for a certain treatment and he feels it is not in his patient's best interest:

> There are a couple of different ways that you have to navigate that. So, part of it is you have to use the legislative framework that exists in Canada, because that's what you rely upon. And that specifically understanding that a patient is allowed to make a decision that's not in their best interest - a substitute decision maker is not. They're obligated to make decisions that are in the patient's best interest. So, for example, if you have high blood pressure and I put you on a blood pressure medication and you say, 'Doc, I'm not taking it,' fine no problem. Depending on how that plays out in the care and a substitute decision maker, they could not easily make that decision to say, 'I don't want this therapy that you're recommending for whatever reason.' They have to act in the patient's best interest. Now, typically, the problem isn't that people don't want any therapy. The problem is most typically when they want therapies that aren't indicated, aren't helpful, aren't beneficial, or aren't in the patient's best interest. And that's usually where you've got to navigate it very carefully and decide what you're going to do with that whole process.
>
> I mean, it starts with a lot of conversation, a lot of education. And for sure, you have to allow the families to experience the results of their decision. So, the typical example on the vent floor is somebody who's very unwell or has had a big clinical deterioration and the family insists on a transfer to acute care to the ICU. And the team may believe, rightly or wrongly, that that's not in the patient's best interest. They're on an end-of-life trajectory and we shouldn't be doing that. So, if in conversation and family meetings and whatnot, the family or the substitute decision maker is not ready to accept that determination of the team, then I will often just say, 'that's fine, this is what the person wants. We should follow that'... I don't know, we're just making our best guess that it's not in the patient's best interest. If you're asking me if you know for 100% sure. No, of course I don't. So, you try a transfer to ICU or two, and then nothing happens, and the ICU says there's nothing more we can do. And now they're there and saying we still want all this done. At that point, you may say, I'm very sorry, but now I'm not doing that anymore. We did it. It didn't work. It didn't happen. But as often as you have to say that the families may say, we now see there was a futility in that, and we're not interested in carrying on that path. A couple of notable exceptions to that are religious and cultural expectations and beliefs that overcome all of that. So, there are some groups who absolutely believe that that is the wrong thing to do, and they want it done a different way. So, this is a value based issue of quality of life versus quantity of life. And I can very easily speak to what I think I would want or anybody in my circle, which is quality. But am I prepared to say that you're not allowed to ask for the quantity; every extra heartbeat you can get you're entitled to? You kind of are in the current system. So, okay, if that's what you want, I don't know that that's any more or less valuable to you than quality is to me.

It is very enlightening to hear the process Jean-Luc may go through when dealing with a family in one of these situations. What he is essentially saying is that oftentimes we must let patients and/or families suffer the consequences of their medical requests,

even when we believe we know it is not in their best interest. Similar to how a good parent will allow their teenager or adult child to grow through suffering their own mistakes. Unfortunately, in modern healthcare with its shiftwork and multidisciplinary teams, some team members may not be fully aware concerning the specifics of a patient's treatment and goals of care. This could be due to scope of practice or to the slow distribution of information across the healthcare team.[120] Perhaps this is where better communication between the healthcare team could go some way to alleviating moral distress in the frontline workers carrying out the physician's orders. If the nurses had more knowledge and understanding that this was a reasonable time limited step wise process they were involved in, they may experience less moral distress when transferring the patient for another ICU admission. Pragmatic solutions for achieving this goal will be offered in the recommendations in Chapter Five.

4.7. Pharmacy

It is well established that pharmacists and other pharmacy personnel experience significant work stressors and burnout.[283] However, the described lived experience of pharmacists may not only be defined by burnout, and we need to consider whether they are possibly experiencing moral distress. Our understanding of moral distress in pharmacists remains limited, with pharmacists often forgotten in studies of HCPs, despite the significant need for comprehending their lived experience.[284]

Pharmacy plays a significant role in caring for patients on the long-term ventilation unit. From admission to discharge or death, they are a vital part of the multidisciplinary team on the unit. It has been shown that moral distress may provide a dependable indicator of constraints in the form of policies and legislation, as well as interpersonal aspects of the setting in which pharmacists practice.[285] Thus, it was felt to be important that the perspective and story of a clinical pharmacist be part of this study.

4.7.1. Malcolm – Clinical Pharmacist

Malcolm has been a pharmacist for over ten years and is the clinical pharmacist covering the long-term ventilation unit.

4.7.1.1. Meaning & Faith (Resilience)

Malcolm was attracted to healthcare and pharmacy after… “taking a pharmacology course in undergrad’ where it was all about how the medications work and… that kind of just piqued my interest. I've always liked health, always wanted to be in healthcare… I like to help people, and I find learning about drugs interesting. So, kind of married both interests together.”

Malcom articulates his understanding of moral distress as:

> Moral distress, I believe, is where there's a disconnect between what you feel morally is right for the patient and their care and for your perspective as compared to what's actually happening. And distress maybe occurs when there's a disconnect between your perception and reality of what care should look like for that patient.

I ask Malcolm if there are any particular experiences where he has felt what he describes as moral distress. “I think it's happened. I wouldn't say at extreme levels, but it's definitely happened.” It is unclear why it was not felt at an extreme level for Malcolm. We know that moral distress provides a dependable gauge of constraints in the form of policies and the interprofessional relationships inherent to pharmacy work.[285] However, because of a dearth of research examining moral distress in pharmacists we know very little as to why Malcolm might feel this way. Perhaps it is his moral resilience; or it may be that the more emotionally distant relationship a pharmacist has with a patient reduces some of the distress.

Malcolm describes himself as an agnostic. “I believe in some higher being. But I don't necessarily believe I need a higher being or a prophet or a cult. You know, no particular one is right or wrong. But I do believe we can't explain everything in this world and the universe. And so, I would classify myself as agnostic.” When asked what supports he has for dealing with existential and troubling issues Malcolm replies:

> I think for me, if a decision was made and implemented and I didn't get to say my piece about why I think this is not a good idea, that would be hard. I think what helps us to communicate my therapeutic information or what I feel is appropriate for care of the patient to the prescriber who ultimately controls the decision. So that helps. Just being able to express that, even though they may not agree with it, at least I've expressed it, and I can document that I've

> expressed it. In the workplace that's kind of how I help manage that. Also talking to other staff members, other pharmacists, to make sure that I'm recommending something reasonable. And again, like I'm not the crazy one, that also helps to alleviate the stress and anxiety related to that. And at home, I mean, outside, I think to me, exercise has always helped in terms of keeping my mental spirits up so that any time I have a tough day, if I can just bike for 15, 20 minutes, just listen to music or something like that, that always helps. Just get my mind off it. Just some time to myself and not necessarily to reflect, but just to focus my attention so intensely elsewhere as well. Yeah, and then the distraction of family and kids that inherently helps as well.

The peer support of his colleagues is expressed as important by Malcolm. He also highlights his need to express his opinion, which speaks to the need for ethically supportive work environments that encourage staff in respectfully sharing their experience and belief. It will be recommended that to nurture our HCPs well-being it is vital we provide adequate workplace supports, including psychosocial support, and an ethical workplace environment.[286]

4.7.1.2. Moral Distress in Relation to - & Emotions

Malcolm recounts some examples of when he perceives himself feeling moral distress and makes a connection with preventable harm to a patient. As with other HCPs in the study he struggles with the notion of having to follow an order he may not agree with:

> Like, for example, antibiotics. A patient is being treated for a urinary tract infection or pneumonia and the prescriber prefers a longer duration than maybe you would. And I feel like my rationale is more kind of evidence based, whereas the rationale for a longer duration of therapy, when I ask are kind of not necessarily evidence based but based on feeling. So, although that may not necessarily harm the patient, causing death for example, it may expose them to unwanted antibiotics and side effects and things of that nature. And so, I find this morally distressing. And as a pharmacist working in this environment specifically, the physicians aren't usually here and you're actually transcribing those orders on their behalf. So not only do I disagree with the length of therapy, for example, but I'm also the one who has to write it down on a piece of paper which would on appearance look like I agree with what I'm writing, even though it's not the case.

I ask Malcolm what if feels like when he believes the treatment could cause the patient some harm:

> Oh, like when I'm writing an order that I don't necessarily agree with. Yeah, it's anxiety provoking. You're worried about the risks. I think as a manager my role is to also review critical incidents from a pharmacy perspective. And I just think about that a lot now where this could be a critical incident waiting to happen or I've reviewed a critical incident like this in the hospital. I can just see it happening. But yeah, it makes me feel anxious, worried for the patients, worried for my own practice and potential repercussions that might have. I think that's why I'm so keen on documentation. But sometimes depending on who you're working with the documentation burden would be, it's too high to kind of put every, put all your feelings down all the time. It depends on who you work with. So now I'm kind of just triaging those types of incidents because I know I can't document my feelings or my position every single time because it would just hinder my ability to see patients and then take care of patients, which is ultimately the most important thing.

We move on to talk about Malcolm's experience in the pandemic. Like Nela, at the beginning of the pandemic he also had a distressing experience of being shunned. Shunning is a form of social control frequently used in small tight-knit social groups to punish those who break the most important group rules.[287] It became common, along with fear-mongering and shaming, as a form of attempted control during the pandemic. To deal more ethically and holistically with a future pandemic, it will be recommended that a wider multidisciplinary expertise and consensus be implemented, with dissenting voices encouraged not silenced, and rigorous engagement with the public.[288] Malcolm describes going on a cruise with some friends and returning home on March 6th, 2020:

> We came back to Fort Lauderdale and the airport, turned on your phone and you just knew things were bad. But even the flights home, no restrictions, no masking yet. And then I remember talking to my bosses, saying, 'am I allowed back at work? What's new?' Like nothing at the hospital had been decided. So, I remember feeling very anxious. Even that weekend I got back on a Friday. On the Saturday, the message was stay home for two weeks and isolate. And then Sunday, the message was come back to work with a mask. And this is like I might have the record as being the first person masked at the hospital actually. And I thought it was ludicrous because there's no PCR testing, there is no rapid tests, there is no way of knowing whether I have this virus. And I just remember, I was actually in my office alone I think at that time, I was between roommates sharing with another pharmacist. I remember I told myself, I'm walking straight to my office, I am not leaving this office unless I absolutely have to. And I think that has probably been the most anxious two weeks that I have had since I've been here, because knowing I work with a vulnerable population. I was taking care of ventilator patients. Nobody had answers. So, it was very, very stressful those first two weeks. And I felt like I had the plague. People would not want to approach me or whatever and or nor did I want to see them. And I was totally

> understanding of it. But I felt for me, that was probably the most anxious I've been at work ever. Forget these clinical scenarios. I think that was the hardest part for me because I think I would feel terrible knowing that an outbreak could have been traced back to me at that point. Me being one of the higher risk people on site, I'm sure in hindsight I would have stayed home two weeks, if the hospital could choose again. But there it is. And that's my moment and then after that having a young child and then having a second child during a pandemic, extremely cautious with everything from doing groceries to seeing family to… I think that was hard for me to just be missing out on a lot of family stuff. I mean, we're a very family-oriented group. So, I'm in my family, so it's hard to kind of and we're all in town and that's the hard part. So close yet so far. So that was also a little bit stressful as well.

Malcolm describes the fear of passing on the virus to a vulnerable patient and feeling responsible for any outcome of that. “So close yet so far" is a vivid description of the isolation imposed upon him and his family. He goes on to share how he found using PPE stressful and the stress of covering the Covid unit at the hospital. “The Covid unit. That I found to be a very stressful environment. And I felt lucky I didn't have to work on that unit. You know, I think I covered it once or twice.” As a parent of young children, he also felt the fear of bringing the virus home. “But my God once you started hearing of all the nurses on that unit spreading between patients and themselves and dropping like flies. Why would you want to do that? And again, I’m somebody with small children. So, a lot of fear that way, for sure.”

Many people experienced a sense of relief when they finally received a vaccine. Malcolm says, “I remember also feeling very a sigh of relief. As soon as the shot went in my arm, I remember a huge relief. Really huge. Really. Yeah. Even though I knew it would take a week or two to kind of actually kick it, it just like you finally got it.” Malcom’s relief was due to his belief that there was much less chance he could transmit the virus to other vulnerable people or family. In regards to his family, considering the extremely low risk of harm from contracting COVID-19 for healthy adults and children, the impact of vaccination on transmission of SARS-CoV-2 not being significantly different from the impact among unvaccinated people, and the now well documented potential adverse effects of the vaccine, it would be interesting to know how Malcolm might feel now in the presence of new data.[213,289]

I am interested to know if as a pharmacist Malcolm has been involved when a family insists on continuing aggressive treatment, even though he believed it was not in the best interest of the patient:

> Yeah, for sure. And I think I had one case where there was a young lady on the vent unit who had a fungus in their intravenous central line. The treatment is very obvious, antifungals and replace the line. But this family was insisting that they keep the line and just to treat with antifungals which is kind of not going to help the situation. So, because you're not really, there's no real source control. So, I think there's always one scenario where they say, 'let's do it this way.' But it really didn't make any sense. And I can remember being there with a physician and we were on the same side and we kind of said, 'listen, this patient might die from sepsis if you don't.' But I don't necessarily know the patient's point of view. Like maybe they were ready to die being in the state that they're around, it was probably a difficult one. And I can't empathize because I'm not in it. But maybe it was really just a signal of the beginning of the end. Inevitably, it was, I think. I'm not there for the family conversations and the social support, but I imagine that there was a family rationale. Other times where they keep ventilators on for patients sort of back and forth, between acute care... stressful for the patient, but they're unable to communicate that because of their vegetative state. So those are situations I've seen over there. And also, those situations where there are multiple family members who disagree on what the best course of action is as well. And you kind of see that sometimes in family meetings.

Malcolm insightfully highlights how the HCP not having the family's perspective, or not knowing the plan and rationale, can lead to moral distress. Again, part of the solution to this is transparent and easily accessible multidisciplinary communication.

I ask if he has been involved in any distressing end-of-life cases or withdrawal of treatment cases. "I think all the ventilator cases can be to some extent distressing to witness and to be a part of for sure… We can't administer MAID (Medical Assistance in Dying) to end a life, but we do have the ability to withhold life saving measures and end a life that way… So, I kind of find it a little odd." Malcolm goes on to explain how he finds being involved with withdrawal of ventilation stressful yet not morally distressing. He provides an interesting and astute perspective into the often-confused phenomena of moral distress and emotional distress:

> I've witnessed them from start to finish. And it's really stressful for me, I think for me, it's not as morally distressing because, one, I feel good the patient's made this decision on their own, and two, I'm helping them die with dignity, which

> gives me at least some professional satisfaction. So as hard as it is to watch somebody pass, I know that we're doing it the way they want and in the most comfortable way possible. I think the only part of the whole process that can be distressing for me is when you see the family members react during the process. Totally understandable. And I think over the years, I've been better at managing that. I don't know if it's a desensitization because I've just seen it so many times. But to me, I just know we're doing what the patient wants. And what better way to go out than on your own terms, because not everyone gets that ability... that privilege really."

4.7.1.3. Healing from & Dealing with Moral Distress

A significant driver of moral distress in a pharmacist could be dispensing a medication they feel is not ideal or potentially harmful.[290] These situations appear to be a trigger for Malcolm's moral distress. I ask him how he might deal with these situations:

> Well, I think to me, it's how I approach most cases with prescribers. My role as a pharmacist is to recommend therapy, medications and durations and doses, and things of that nature. And I think I just kind of express where my thought comes from and why I would suggest maybe a shorter course of therapy, whether that be something related to the guidelines, something that even the hospital has kind of recommended based on order sets. So, I try to provide the rationale and say why it may be better for shorter duration versus longer to the prescriber and help them make an informed decision. And so, I think that helps me relieve some of the anxiety around these morally distressing situations. But ultimately when they don't take your suggestion, then it's, then again, so transcribing on something that I don't fully believe in. And that's kind of the way I mitigate that too, is like if I really felt compelled to, if it really bothered me, I'd probably document in the chart in my own chart notes to see that, hey, you know, this is the issue. This is what I think is important. This is what was done. And I don't necessarily agree with the course of action. So that's definitely happened to me a few times where I felt compelled enough to document because the disconnect was so strong, a bit stronger.

Inter-professional collaboration between pharmacists and physicians has been linked to improved patient outcomes,[291] so why would a pharmacist be hesitant to discuss his concerns or opinion with the physician? Some documented reasons for why collaboration may vary include factors like shared values, relationships, role definition, and trust.[292] Due to fear of litigation, the physician may be practicing defensive medicine, by prioritizing their professional knowledge and values less in the diagnosis, treatment, and care, and more from an attitude of self-protection.[293] Often the HCP, like most humans in many situations, is simply afraid of confrontation. For this reason, a

supportive collegial network is important to provide a sense of safety and encouragement and will be recommended. Malcolm provides an example where a physician may increase medications rapidly and not necessarily give an adequate trial at certain doses before escalating. He explains how the physician is trying to achieve what they feel is an evidence-based dose but at the same time, they're plummeting the patient's blood pressure, putting the patient at risk for falls. "You talk to the prescriber who says, 'no, this is what I want to do.'' Even though you're trying to be the voice of reason, it's difficult to get through to some people, or they just feel really strongly a compulsion in their own perspective that this is the right thing to do for the patient." In these cases, Malcolm reaches out for peer support. "You ask your colleagues, and you say, 'hey, am I crazy here for recommending something like this; why is the prescriber not agreeing with me?' But, with certain people, prescribers and physicians, nine out of ten times I know that I'm not crazy and that my recommendations are sound and reasonable."

Malcolm explains the discomfort of asking a prescriber to review their order and rationale:

> We disagree on this therapeutic discussion, or this thought or care for patients, but I've never gone back to tell them, 'hey, you put me in a morally distressing scenario.' I've always kind of felt that to be... I don't want to say it's unprofessional, but it's always a hard conversation to have because you have to continuously work with these people, right? So, yeah, it's difficult to say because you don't want them to... you don't want that conversation to negatively influence the impact you could have on future patients, I suppose."

I ask Malcolm how one might mitigate disagreements between patients, families, and the healthcare team. Malcolm explains that… "a living will is a great idea. It's obviously not possible for everybody… preparing yourself to reduce future stresses as much as you possibly can, whether it's a financial burden or care directives or so forth." So, making sure that your family are aware of your goals of care, I question. "That's right. 'I want to be absolutely clear. This is what I want. Even though I can't communicate, and you have to do that for me. I want you to do it.' So, you have those conversations with your wife and your family. Just make sure everyone's on the same page."

If Malcolm had a colleague, or direct report, sharing a particularly morally distressing episode with him what advice or coaching would he give them? “Well, I think to me it's just listening. A lot of it is listening. That's because you should just listen to what they have to say and really understand their perspective before you comment.” Wise advice, and what strategies might he also use. “Talk to your prescriber, explain why, document your decision. Ask other colleagues so that you feel your decision is actually reasonable. That's happened before where physicians I've worked with put other pharmacists in those same really distressing situations and they feel just as handcuffed as I did.” Malcolm’s use of the word “handcuffed” is a revealing insight into his feelings of helplessness during these encounters.

Finally, Malcolm shares how the hospital’s “Just Culture” provides an environment conducive to dealing with and healing from moral distress:

> One way that perhaps moral distress is mitigated in this institution that I think is a novel approach is those "Just Culture" explorations. I feel like it gives them a path. It gives all the other staff the ability to express their feelings and attitudes towards a particular situation where they feel heard and can actually improve things… So, in morally distressing situations sometimes things don't go well and they negatively impact, but this hospital has a process to evaluate that and to potentially improve processes and mitigate future moral distress… I think a lot of moral distress in pharmacy is the process and not necessarily the people. You put people in processes and whenever there's discord, sometimes it's not necessarily personality discord all the time. Sometimes it can be a process issue, too. And internally within pharmacy, we see that, too. And I guess we really haven't talked about that. We've talked more about the context between pharmacists and the rest of the team, but within pharmacy, I can tell you that that's where a lot of moral distress comes from.

He then provides an excellent example, which will be recommended in Chapter Five, of how implementing computerized physician order entry (CPOE) may reduce errors, and thus, moral distress for pharmacists.[294] Malcolm explains how CPOE… “would eliminate it. Because a physician wouldn't be able to even enter the order unless all the fields were included. There's not a person stopping you, there's a computer, inanimate object, stopping you from proceeding.”

Malcom’s testimony of his experience as a clinical pharmacist on a long-term ventilation unit is illuminating, as it adds to what is at present a dearth of literature on the

pharmacist's perspective. A significant driver of his moral distress is feeling "handcuffed" i.e. helpless, when disagreeing with the specifics of a prescriber's order. He is powerless (unless the order is potentially dangerous) but not helpless. He acknowledges he is not helpless by offering wise and pragmatic advice for how pharmacists and physicians can improve collaboration. From 12 Step spirituality we are given the insight that it is ok to be powerless so long as one does not believe themselves helpless or is without hope. Teaching HCPs the experiential and conceptual difference between powerlessness and helplessness in moral distress is of vital importance. It will require time and education for HCPs to become comfortable with the knowledge that for the most part they are powerless over much of what happens in the hospital; and it is ok to be powerless and to accept that. So long as they have help and hope. This will form one of the recommendations in Chapter Five.

4.8. Respiratory Therapy

Respiratory therapists (RTs) are a vital part of the multidisciplinary healthcare team on a long-term ventilation unit. Respiratory therapy is a technical and highly skilled specialty that is critical for the safe and effective care of patients with cardiopulmonary disease. RTs evaluate, treat, and care for people who with respiratory issues, using oxygen, medicines, and mechanical measures to help them breathe more effectively.[295] They are a necessary part of the treatment team involved in end-of-life care, especially when a patient undergoes ventilator withdrawal on the unit.

The literature on moral distress in respiratory therapy is far more limited than that of moral distress in nursing. However, what research there is shows RTs do experience moral distress.[296] In fact in Canada during the pandemic a quarter of RTs reported considering leaving their position because of moral distress.[297] Those that were thinking of leaving reported increased moral distress and negative psychological and functional outcomes in comparison to RTs not thinking of leaving, with more than fifty percent of those considering leaving scoring above the cut-off for possible diagnosis of PTSD.[297] The study authors write that broader, organizational issues may play an additional role among Canadian RTs, and identify this an area for further research.[297]

4.8.1. Nadia – Respiratory Therapist

Nadia has worked in healthcare for more than 25 years. Much of her career, like many RTs, was in critical care, ICU, & ER. She had worked in acute care and the long-term ventilation unit for the past decade, however since the pandemic now only works with the long-term ventilation population.

4.8.1.1. Meaning & Faith (Resilience)

Nadia explains what attracted her to respiratory therapy:

> I always wanted to do something in healthcare but did not want to be a nurse, did not want to be a doctor, and didn't know what else was there, so just started looking up some catalogs and did a job shadowing one day and I like the variety of respiratory, where you see lots of different patients in a day, you do lots of different things.

I ask what specifically attracted Nadia to work with the long-term ventilation population:

> It's nice being able to spend time with the patient. In acute care you're in, you're out. You don't have enough time to spend with them. Here you get to know them a bit better. You can work on different things for their quality of life as opposed to just the pure medical treatment and when you want to try an intervention then you have the time to actually sit with the patient, try it out more long term rather than say ‘oh, it's been 15 minutes, I got to go.’ With time we've been getting more and more complex patients, very different patients. Patients can actually interact even more and it's nice getting to know their personalities and who they are and what we can do for them.

It is obvious that Nadia feels an increased sense of meaning when caring for patients that she has developed a deeper sense of connection with. This dynamic also benefits patients, who feel that an important aspect of compassionate care is to be treated as a person, not just a disease.[298]

Nadia discusses what are some of the challenges and rewards of her work:

> It's rewarding and challenging trying to find a way to get our patients to communicate. So having a voice is usually the biggest thing for these patients. So, they may have tried in the past. They might not have tried in acute care, and they've come to us and we've seen some changes. And then we said, ‘hey let's see if we can work on getting you a voice and being comfortable.’ So, it's been rewarding when we can actually give them a voice that can communicate

> that people can understand what they're saying. The challenge is getting to that point because often we can spend time, but we can't always spend the full amount of time we want to. So, it's a much slower process and then when it starts backfiring on us and not working as well because patients are getting more compromised because of their disease or something. It's almost like they had a voice, and now it's being taken away, but it's nice that we have a team, so they also work to find different communication methods. So, I think communication is like the biggest one.

Without doubt the inability to be understood as a patient is not only deeply frustrating but also detrimental to their health outcomes. Descendants of Chinese and South Asian ethnicity in Ontario with language barriers, were more likely than the non-Asian population to receive aggressive care and to die in the ICU.[299]

Nadia then touches on the guilt she feels when discussing the patient's dependency on others and is another HCP who uses the term "prison" to describe some patient's experience. "They're here long term, this is now their home, but they're attached to a machine. But yet they feel like they're in a prison because they can't go anywhere on their own… it's heartbreaking. These patients are kind of stuck here, reliant on us."

Nadia articulates her understanding of moral distress as:

> When you think something should go a certain way based on your ethics and your morals and right and wrong and experience. But the situation, the patient, and the family, the system, go the other way, or make you do something that you don't really want to do, or you don't think is right.

Nadia's phrase of being made to do something she does not want to or does not think is right speaks to that sense of helplessness so prevalent in many people's experiences of moral distress. I ask her if she thinks about work when she is home. "I've been doing this so long and seeing so much of it I kind of shut things off." However, she then quickly recalls a distressing incident from her past:

> Yes, I still remember the very first code I was ever at when I was a student. I was just suctioning them and all of a sudden, I got blood, and I was like telling my RT I'm like I'm suctioning out like copious blood and then the heart just tanked and we were in CPR. I still remember that day. And I went through it, and I was OK and then I was good. As I walked out and someone said, 'are you OK?' And then I started crying.

Nadia recalls another time when she was left shaking after a routine tracheostomy change turned into a medical emergency. “I don't think I dwell on it unless I feel like I did something to cause it, or if I did something terribly wrong, I think then it would haunt me.” If Nadia had done something, in her words… “to cause it or did something terribly wrong” it would likely result in a moral injury. Haunted is indeed how many people feel who suffer with an untreated moral injury.[86]

I ask Nadia if she considers herself spiritual or religious. “Yeah, I would say I'm spiritual, religious, but not so much into all the rules.” What does that mean to her. “I believe there's a higher power, like a God. I believe we should all be kind to each other. I believe that we have an intellect to help us with all of this technology that we have and everything. But I also feel like life at a certain point has to end.” Life at a certain point will end for all of us. Often when receiving a terminal diagnosis, the families of dying patients experience a phase of significantly increased emotional stress that can manifest many of the same feelings felt with moral distress. These feelings may include hopelessness, anger, and guilt.[300] Differing perspectives between the HCP and the patient’s family regarding whether we are prolonging life or prolonging death, are a significant driver of conflict and moral distress for many of the HCPs on the long-term ventilation unit. Nadia explains her personal perspective:

> We are born and we die, we know we're all going to die. The question is how? And I don't believe in suffering or prolonging life. If there is no quality to it, right? I also feel like you also have to think about everybody else around… Like if I was a quadriplegic, I don't know if I want to keep going. But there's a lot of quadriplegics with quality of life. But if I were to be stuck to a ventilator and not be able to do things and not be able to communicate, stuck in a hospital, like I don't know that I would want my family to be burdened with all of that, and that's the part I also see a lot of the patients don't see that burden on the family. Or the family don't even recognize the burden on them… There's some kind of power, we all die at some point and all the machines in the world, they're not always going to give you back that person, right?

Feeling that one is a burden to their family and loved ones is a common source of guilt and angst in many patients with significant limitations and is central to asking for medical assistance in dying (MAID) for some patients.[301]

How do Nadia's spiritual beliefs affect her ability to deal with issues that could result in moral distress:

> When patients do pass away, I feel like their souls are, they're at peace. Especially our patient population, who are already so sick. It's not a sudden something just happened… I think you know every person is their own individual. Every person deserves respect and dignity. So, I try to show that with patients and families. No matter whether I'm talking to a brick wall or not. It's they have their own decisions, their own beliefs, their own values. So, I try not to impose mine on them. I mean, I might talk to my fellow RTs to kind of vent behind the scenes but in front of them I won't be doing any of that. When I just talked about venting, I think it is important when the whole team is feeling something that we do actually talk about it and get our feelings out about it. Just to know that we're not alone, and if we are, then it's like, oh, wait a minute. Why am I thinking this way and nobody else is right. Which doesn't usually happen. Usually, we're all kind of feeling the same thing. But you also don't want to force anything on the families or patients, just try and treat everyone with respect.

The importance of peer-to-peer support is once again highlighted by an HCP on the long-term ventilation unit. How vitally important it is for HCPs… "to know that we're not alone." That sense of identification and safety is paramount to the HCP's ability to process moral distress and why peer-to-peer support is a primary recommendation from this research.

4.8.1.2. Moral Distress in Relation to - & Emotions

When Nadia discusses her experience of the pandemic it is interesting to note that once again an HCP uses the term "prison" to describe what patients felt. Also expressed is her sense of guilt at the inequality of some pandemic restrictions:

> We get to go home and have our lives and during COVID it was even worse because there were all those rules about masking and everything, yet we could go home. We could take our masks off, we could go shopping, go to a movie even and things like that, but they were stuck here. There were all these quarantine rules. If they went out home for the day, they'd have to come back and quarantine for ten days in their room. Whereas we saw it was almost hypocritical because we could go out, we're not quarantined, and we come into the hospital. Some patients did say it felt like a prison, and I can see why.

I ask Nadia if she has witnessed HCPs giving, what she perceives to be, false hope. She expresses her frustration at a patient case involving the physician who no longer

works on the unit. This case is mentioned by multiple study participants and caused significant moral distress:

> There's a patient who is on a ventilator. Family, patient, they have hope she will walk out, not be on a ventilator. We always have a little bit of hope that something like that can happen, all depending on the disease process. But we also watch for signs of strengthening, signs of change. All of those different signs and these signs weren't happening. Yet from the beginning the physician they had was feeding into their hope. And because of that, they did not trust the team at all… even a year and a half into it they still believe that, despite the team being very blunt, saying 'it's not going to happen. Nothing has changed. You're even weaker.' It wasn't just me. It was the entire team, felt like this. And it was the one physician who was the main person making the decisions. Interacting with the family and just giving them this hope, this hope, this hope. And how do you? I don't know, how do you break that hope? When somebody's fostering it, right? It's frustrating because you can only do what you can do within your professional capacity and you don't want to overstep what the physician is saying or doing, but we do keep reinforcing sort of the reality. But it's almost like talking to a wall.

What might drive this false hope? It is not surprising that families on the long-term ventilation unit, in their despair for a different reality, cling to whatever hope they can. The phenomenological nature of hope and despair has been described in terms of the failure of one's social resources, the dimishment of one's social world, and a disintegration of self-representation.[302] The reality is that hope on the long-term ventilation unit may involve self-deception, on the family's part, concerning the sociomoral reality of what is actually happening to the patient.[302]

Nadia is asked if she has had to follow a family's insistence to continue aggressive treatment, even though she believed it was not in the best interest of the patient. "Why are we doing this," laments Nadia. This often-heard phrase, strongly associated with moral distress, is typically asked in tones suggestive of frustration, helplessness, and sadness.

> There have been patients that maybe they never had a tracheostomy before, and they were here, and they have a long-term disease. You look at, and again I'm putting my own version of what quality of life is, but it doesn't seem like a big quality of life. Yet the family wants everything done. They end up in ICU, they want everything done so the medical team does everything. They come back here with the tracheostomy, maybe a ventilator, and you're just shaking your head going… 'Why are we doing all of this?' And it just feels like it's the family

> wants it. The healthcare system allows it, so we have to do it. There's another patient here, family has hope that she will still get better. Family thinks she can communicate. We've assessed communication, there is nothing, there's no consistency, there's nothing, and you're just kind of sitting there going… it's hard to look at this patient just lying there with no reaction, no nothing, yet we're caring for them. We're trying to keep them alive, but we're not sure why, other than it's for the family.

I ask Nadia what this feels like. She articulates that she thinks it is probably harder for the nurses as they are doing everything for the patient. She makes the point that… "with me, we're just sort of in and out. We don't have as much to do." Do the extended periods of time, necessary in a nurse – patient relationship, result in a deeper connection at the human level, thus leading to greater felt moral distress? Would the brief, mechanical interactions of the RT reduce the severity of felt distress? I press Nadia as to what specific feelings a case like this might generate. "I guess it's sadness. Frustration."

Interestingly Nadia then mentions the ethical principle of justice. Justice in healthcare ethics refers to a fair and equitable distribution of health resources by promoting the financial strength of the healthcare system for the greater good of society.[303] "It's also just she's taking up a bed that perhaps somebody else could be using, because to me it doesn't even feel like it's a person. If that. I mean, it sounds heartless." She explains how in those situations… "It's hard to interact, so that's when we get the people who are better at this kind of stuff, like our spiritual care, and our social workers to try and talk to the family… it's very hard to talk to families who can't let go, who have a lot of hope, when nobody else sees the hope."

We now discuss documentation and communication for RTs on the long-term ventilation unit. I specifically ask Nadia if she has ever seen patient care negatively impacted due to poor team communication. "I see a lot of that. I feel it is hard to get the consistent message across because there's so much staff… The allied health and the physicians we're more constant, with nursing staff you have different nurses, different patients." She then speaks about a commonly expressed frustration with electronic medical record systems (EMRs). "It's hard because Meditech (EMR) is confusing, and nobody's going to read through everything in there. They also don't know how to get through and read other allied health notes half the time, but they don't have time because they're doing

their patient care right.” Nadia then makes an interesting observation as to what she sees affecting patient care. “I find that if there is poor patient care it's because there's a lot for people to do. But they're not asking the questions when they don't know something.” A question for future research is why are staff not asking for help? Is it timidity, fear of asking questions, or that they don’t know they don’t know? I ask Nadia about her documentation notes. “Nobody's reading them. Things go in there and then they don't get updated because perhaps I wrote it in one section, somebody else wrote in another section, something changed… but nobody thought to look there and then a year later, you still see that old note.” Perhaps there is there too much information. As Nadia says… “There's a lot of documentation. So, it's no wonder that there's a lot of it that's inaccurate or wrong because there's so much documentation.”

We move on to discuss Nadia’s experience with patients and/or family members who may be abusive at times. She’s grateful for the support available to staff. “Luckily, I haven't had too much happen with me. I mean it's good that there's manager support, code whites that can be called.” Nadia like many staff feel that the violence flags posted outside patient’s rooms, signifying a history of violence, lose their effectiveness as they are not updated. Some feel that these public displays may result in stigmatization of patients, and a perception that patient rights have been infringed.[304] Nadia explains… the violence flags, which I feel like sometimes it's on for too long, I feel like this does need to be readdressed at some point.” She then shares an example of an interaction with a patient’s family member that many HCPs on the unit may be able to relate to:

> So, it happened once where a family member was getting angry about a tracheostomy hood… Like they pick on the smallest things. He was holding it and showing it, and I said, ‘can you just pass it to me, and I'll show it to you,’ and he wouldn't pass it to me. I said, ‘I can't show you, unless you pass it to me.’ He kept holding it up higher and of course I'm short anyway, so then I just stood there and then he did like a little tap, like a little push on the shoulder, or whatever. And then I backed away and I said you can't touch me like. You can't do this. And then he was, he was escalating. He was getting more angry. He was, ‘I'm going to go down to the manager,’ and I said, ‘by all means.’ But I went to the manager first. But it makes it hard it. I mean the patient’s fine, the patient was not the issue, it’s the family member.

Nadia then articulates the negative consequences that these altered relationships can have on patient care. “He still does those things, but I'm more hesitant to approach him

about things. If things were to happen, if there was something that I had to explain or do something, I know I would bring a second person with me." So how would Nadia deal with this situation if it was a patient… "If it's a patient who's being abusive, I would just say, ok, look, I don't need to deal with this. I'm going to make sure you're safe. Everything is connected. Alarms are on. I'm walking out of here." Respectful and assertive. How might a RT feel in these situations:

> I mean it's nerve racking. Your pressure goes up because I'm not usually somebody who gets angry… you're trying to tell them how things work, and yet they're getting angrier and angrier and not listening to anything you're saying so, you feel like. At a certain point, it doesn't feel like a safe zone. Feels to me with a family member, feels less safe. With a patient it's kind of like what's the patient going to do other than hurl words at you right? I mean, our patients can't really do a lot. But the patient could throw things. Yes, I would be scared. I'd be worried. I'd probably be scared the next time I went in the room. Depending on who the patient is. How are they going to act. Actually, we had a patient who we were following for smoking cessation. He was constant code whites, and he would hurl things at people. So yeah, I probably didn't see him as much as I probably could have.

Once again Nadia gives a powerful example of the negative impact behavioural issues may have on the delivery of care in the hospital. "If I read the notes and he'd been yelling at nurses we won't go see him today. We'll go see him another day… it does affect you in that way, right? Like if you don't have to go in then kind of keep your distance a bit." Nadia believes that the behaviour of patients and families is continuing to worsen:

> I feel it's gotten worse. I think because we have a lot more technology and resources and surgeries that are being done, and Google, and Internet, and patients are asking for more. Doctors are offering everything. Patients are becoming more chronic, they're getting sicker. They're definitely sicker coming in here… I find the more chronic somebody is the more behaviour issues there are, be it anxiety, be it depression, be it a sense of entitlement. I don't know. Controlling. I mean, we've always known that they become much more controlling, they can't control, they lose control. So, they try to control whatever they can control.

During their time in hospital patients may feel their lives are disrupted, day to day events suspended, and control over time is lost, often leading to feelings of loneliness, anxiety,

and depression.[305] Nadia then offers a truism familiar to all who toil at the bedside. “Unless you work in healthcare, you don't understand healthcare.”

We move on to discuss the issue of unclear or inconsistent goals of care and treatment plans. Nadia explains her frustration when a patient’s code status remains full resuscitation, and she feels the decision is not in their best interest. “So, they’re full code right, which is frustrating for the staff, because then you have to do CPR, and do all of this for the patient when you know full well… they have something where CPR is not going to improve their quality of life in any way.” Why might this happen? “I feel like those discussions aren't always happening early enough. I mean, sometimes they fall through the loops.” For Nadia these issues can be improved proactively with… “social workers who are a bit more on top, like it hasn't been addressed yet, or the manager going you need to address this, or if things are changing, we're like we need to talk to this patient.” And what may happen if they remain unresolved? “Sometimes they don't make decisions and then it's trying to explain to them well, if you don't make the decision, all of this is going to happen, and they still don't want to make a decision. And then everything happens.” The common feeling in these situations for the HCP is... “it's kind of frustrating that, you know.”

4.8.1.3. Dealing with & Healing from Moral Distress

In discussing the situation when the multidisciplinary team disagreed with the direction of a treating physician, I ask Nadia if it could have been resolved in a better way. “See, I don't know that it could have been resolved other than removing that one person who is giving the hope. Which is what ended up happening.” She then adds how this improved the situation. “The family still has that hope. But now you don't have somebody constantly feeding into it. So, they're a little more accepting of what the team is saying, which makes our jobs a little easier, makes it also easier to speak a little more bluntly about what we're seeing.”

I ask Nadia what can be done in situations where we are providing aggressive treatment for a patient who is most likely going to die regardless of this treatment and is suffering.

> Some patients are still full code, or they still want full treatment, but you just don't know why. I mean nothing's gonna change… What is the purpose? What

> are you trying to achieve with this? Why can't you see reality? What are you, you're just trying to let them live. It's going to be worse. And me, while you're praying through all this suffering all this anguish. I don't know that it can be improved other than a physician clearly not giving the choices, basically just saying you know what? No. You know what? We can't. We can't do this. But we're in a healthcare system where all these things are available, and if you don't offer it while the family will… then talk about lawsuits and everything. So, I think that's why it's available, it's offered. Because you have to offer it.

I now ask Nadia if she ever participates in care that she feels causes unnecessary suffering. She talks about the special requirements and resources needed when transferring patients on the long-term ventilation unit and how exceptions could be made. “Clinics don't appreciate that our patients are on a ventilator… that they require somebody to go with them… the whole transport there can be tiring for the patients… You show up, they look at them for five minutes and say you're good. Goodbye. Patients who can't even talk.” I inquire as to how could this be improved. “Why talk to the nurse? Talk to the family! Even here to go to the clinics below the vent unit, same thing. It would be nice if they could come here, just for our ventilated patients, because it's a lot of work… to go downstairs for a two-minute appointment. A lot of them could be done on the vent unit.”

I now offer Nadia a magic wand to implement measures at all levels to mitigate the drivers of moral distress in the hospital:

> I think for difficult patients having a set plan. So that everybody is working the same way, and of the whole offering of hope and this and that. Communication, things that people could be saying or doing… so that everyone were on the same page… for the more difficult patients.
>
> We need a debrief or just to talk about that one patient and the troublesome family or the troublesome patient or something like that. Having the team meeting there, I mean. We've started to rely a lot on, like our chaplains and they've been very effective with some of our patients, and I think it's because they're the non-medical people, right. And they can sit there, and they can listen… It's a chance for the patients to vent their frustrations or their family to vent. Like it would be nice if we had psychologists or psychiatrists for patients and family. Because I think if they could get out their thoughts and work through their thought processes and they had somebody helping to guide them along that path, especially for like our kind of population, I think that would ease some of the distress on the healthcare team. Because I think often, they're acting out because either they don't want to give up or this is frustrating because nobody's

> doing anything to help, or you know they're not getting better, and they don't have the coping skills. So, I always thought it would be nice if we have psychology or somebody there for patients and families, I don't think we have either.

I mention to Nadia that I had worked in a previous hospital that had a monthly support group for patients and their families, where they could come together in a safe space and express their concerns with people in a similar situation. A facilitated peer-to-peer support group for patients and families. Nadia makes a wise point that… “it has to be guided otherwise the families start saying, ‘oh the nurse didn't do this. That didn't happen. They didn't do this.’ And then they gang up and it all becomes negative.”

I ask Nadia her thoughts on the support provided to allied health, doctors, and nurses. “Our manager's awesome. So, we can come to her anytime with anything. We can always reach out to the chaplain if there's something personal or if we're worried about something, and she'll do debriefs if we need to do debriefs.” I also feel that the support for the staff on the long-term ventilation unit is excellent, and spiritual care deserve a lot of credit. Nadia then looks at the issue from a more organizational level:

> I feel the administration is supportive. Like respiratory, I don't know about the rest. I feel like when we had that big issue with the one doctor it was easy to approach higher administration. Ask what we need to do. And we did it. And then they actually did do things about it afterwards. I understand sometimes things take a long time to get things done.

How did the situation with the physician get resolved, I ask:

> Oh, I think there were many, many complaints. From nursing, from allied health, from a lot of people and so, they had to investigate it. Go through the charting and do different things and then they approached the physician. I think he, I don't even know the end result, if they fired him, or if he just resigned and said, ‘I don't need to do this.’ He'd already been talked to a few times. But it certainly left a gap for this one specific patient. It was hard for them and hard for them to trust, and the physician they ended up getting was like the ultimate opposite. So, for the patient and the family, that's a very hard thing to deal with. So now they have a more in between physician, which we finally found… You need physicians who are kind of in the middle or moderate, you can't be flipping from extremes. Makes it hard for patients.

I ask Nadia for her final thoughts on what we have discussed:

> I just wish our system was different… A lot more support at home. Because patients are much happier at home. And there'd be a lot more consistency at home, but they also need more staff at home. If you have a few doctors who are saying you should not escalate care, this is going to compromise them. It is not going to do them any service, because there are patients like that. I wish we had a system where you didn't have to go to this board, if you could get a few doctors, somebody to look at the whole picture. Sign off on it and say, 'nope this is not worth our healthcare dollars.' It's all about money. It's not worth putting them through all this suffering and this anguish… If the family still says, 'nope. I want to do everything.' Well, perhaps they should pay for it, because as soon as they have to pay out of pocket it becomes a different world.

Nadia brings a necessary, and often neglected, HCP perspective to this story of moral distress on a long-term ventilation unit. Her testimony shows how as an RT she sometimes asks the question of many on the unit, "why are we doing this?" Nadia is able to bring some pragmatic ideas forward that may allow the question to be uttered less frequently. Her suggestions for improved multidisciplinary communication, mental health supports for patients and/or families, ethics support, and team debriefs for challenging cases are recommendations from this research and will be discussed in Chapter Five.

4.9. Nursing Management

Nurse managers have been shown to experience deleterious effects on their physical, emotional, social, psychological, and spiritual well-being from moral distress.[191] Nurse managers may suffer moral distress when they are unable to sustain effective unit functioning and feel caught in the middle between their staff and unit needs and organizational requirements.[306] Nurse managers may also experience moral distress resulting from a perceived lack of autonomy, internal and organizational constraints, and increased workload.[307,308] These system-level causes of moral distress are frequently seen among nurse managers.[306]

There appears to be some correlation between a positive ethical climate and lower levels of moral distress, and a benefit from positive relationships in coping with moral distress.[191] Some suggested measures for tackling the moral distress of nurse managers include, leadership development and, as recommended in Chapter Five, the creation of spaces in which moral distress can be openly discussed.[121] Nursing leaders

may experience conflict between the values of their workplace and their nursing values, and giving nurse leaders training related to ethical decision making may enhance their chances of job satisfaction and success.[309]

4.9.1. Eleanor – Assistant Unit Manager

Eleanor is a registered nurse and the assistant manager on the long-term ventilation unit. Prior to becoming the assistant manager on the unit, she worked as a staff nurse on the long-term ventilation unit and has been at the hospital for the past decade

4.9.1.1. Meaning & Faith (Resilience)

Eleanor explains how she is enjoying her role away from bedside nursing. “I'm enjoying the regular hours. I'm enjoying having a bit of a break for my back to be honest, but I still have the same relationship with the team and with the patients. So, I get to interact with them still.” Eleanor makes the point that she still has contact with the patients, and this connection is of importance to her. Eleanor describes how as a bedside nurse on the unit she would… “spend a lot of time caring for the patient, a lot of time to build trust, getting close to them, getting to know them before, what their life was like before their accident or before their illness… it's a very heavy unit, emotionally and physically.”

For many of the ventilated patients the unit becomes their home. I ask Eleanor how that increased length of stay could affect the relationship that develops between the nurse and the patient, and the patient's family:

> I think it allows the nurses to build a strong relationship with the patient in terms of knowing them, knowing about their personal lives and the trust that you build. So, it can be very rewarding to have those relationships with patients and it can also be very difficult at some time, certain times when they're not doing well. Or when they pass away… When you know someone for a couple of years, even though you know that they're here and they're not going home, they're not getting better, it can just be a, feel like a really big loss when you spend 40 hours a week with someone, and then one day they're gone.

I know from teaching undergraduate nurses and new graduates that many share they would like more education and support on dealing ethically and emotionally with grief. We know that repetitive exposure to loss and suffering can lead to grief, which may eventually lead to the development of compassion fatigue.[310] For the nurses on the

long-term ventilation unit it will be recommended in Chapter Five that continuing education and support for dealing with grief is provided. Eleanor moves on to share, with gratitude, some of the rewards and challenges of working on the long-term ventilation unit:

> Some of the most rewarding is building those relationships. And when someone acknowledges all the hard work you do, when someone says, 'thank you,' it seems like a little thing. But when you are slaving away. That sounds bad, but yeah, it's nice to be recognized and acknowledged and have patients be grateful. And it can also be difficult on the other hand, if their anger is directed at you; that can be really difficult to not take it personally and to respond calmly and professionally, and in a way that's empathetic to their situation. For some of our patients who can't speak for themselves, it can be challenging caring for them, if their family member has a different care directive goal than the patient had agreed upon before they were no longer able to speak. So, we have had that in situations where a patient said, 'I don't want this treatment.' They're no longer able to speak and the family goes ahead with that treatment that the patient specifically said they didn't want. That can be very distressing for nurses and myself included. I've seen that on this unit.

What she is describing here is moral distress. Eleanor then describes the tightrope that many HCPs feel they walk on a daily basis. "So, it's a fine line between helping the families and respecting their wishes, while also keeping the dignity and autonomy of the patient in mind." This powerful sentence highlights the conflict felt by HCPs when they believe they are not acting in the patient's best interest, due to the wishes of family. Is it surprising then that in these situations a caring human being may feel sadness, guilt, and frustration. All appropriate feelings I would argue in light of the situation the HCP sees themselves trapped in. What emotions might Eleanor feel in these cases:

> A lot of anger and frustration. It seems like a lack of respect in my opinion, especially if it's a family member or a loved one that you know you trusted this person. You put your health in their hands, and you specified your wishes, and for that person that you love and trust to go against it, to me seems like a betrayal, and it's very difficult, for me personally to reconcile with because I think of how would I feel if I was in that situation. At the same time, I realize that families who are not in the healthcare field may not understand that they're prolonging suffering; and they may think that by doing all these treatments and measures that they're doing the right thing; and they feel that because they love the person, they want to do what they think is best. But it's not always in line with what the patient wants, or what really is best for them in the moment in terms of causing more pain or suffering.

I ask Eleanor what she believes moral distress to be:

> I think I understand it's when nurses or people are put in a situation where they're asked to do something that either goes against their personal beliefs and that can be difficult, or if a healthcare provider knows the patient has expressed certain wishes and the family tries to override that, and we go with the family wishes instead of the patient wishes.

In these morally distressing cases do the nurses ever speak to Eleanor and tell her how they're feeling and how they are being affected:

> Absolutely. When I was still working at the bedside, a lot of us would vent to each other and speak about our frustrations and how we felt. Like the family didn't understand and that we didn't feel supported by the physicians or by management to have these difficult conversations. Or we weren't… kept in the loop. Maybe you know no one was communicating what was actually being done with us… The nurses would also feel sadness. Frustration. Helplessness… trying to advocate for someone and feeling like they're not receptive to what we're reporting back to them, what we're seeing.

It is interesting to note Eleanor's forceful use of the word helplessness. Helplessness and powerlessness may have particularly specific meanings in 12 Step spirituality and when applied to moral distress.[311] This will be further addressed in the recommendations and conclusion of Chapter Five. Dayton articulates this difference as:

> Powerlessness is a conscious act of surrender and implies my own recognition that I cannot control people, places and things. Helplessness is part of the trauma response, part of the collapse that any human or animal goes into when they feel that there is nothing they can do that will help to change things for the better. When I allow myself to shift into a chosen state of powerlessness, I make a profound move inward and upward. The helplessness that I carry… that feeling that nothing I can do will make a difference, transforms into a spiritual recognition and I can surrender my wish to control people, places and things in order to feel safe and okay. I find safety and comfort in my Higher Power, I let go and let God.[312]

It will be vital then that we clearly differentiate between helplessness and powerlessness when attempting to help our HCPs process moral distress. If the HCP has a religious or spiritual worldview then guiding them from a passive state of helplessness to powerlessness can be achieved by their faith.[105] For those of an agnostic or atheistic outlook a secular explanation of the futility of non-acceptance and

training in radical acceptance[x] may improve their ability to implement both emotional acceptance and cognitive reappraisal.[229]

I ask Eleanor how those feelings of helplessness, anger, and frustration affect her over time. At the end of her reply is the fact that moral distress and burnout played a part in her decision to move away from bedside nursing into management:

> For me it was mental burnout. A lot of anxiety. Even when I would be at home, I would be thinking about situations and feeling emotionally charged by that at home. Also, just feeling sort of like your profession isn't really valued when you're showing up day-to-day for someone and maybe not always kept in the loop or involved and decisions on how to proceed about difficult decisions, about treatments. Just knowing that the physicians and management are aware of those situations and that they're hearing the nurses, what they're seeing on the front line and taking action to communicate that with the family in a supportive way with a team of professionals so the family can understand the situation better, maybe that would be helpful. It just doesn't feel good over time. You feel like no one's listening. Feel stressed. That's personally why I decided to take a new role away from the bedside. And I do feel less anxious dealing with certain situations.

Eleanor goes on to say that… "It's a very challenging unit and you have to be a really strong person to show up every day and be the best version of yourself for other people." Also… "I think it's really important to take care of yourself and I think nurses may need help with that a little bit." I inquire as to how she takes care of herself. Once again, the importance of peer-to-peer support is highlighted. Eleanor emphasizes the point that although team talks and sharing feelings are important, the nurses need to feel heard and that their concerns will be listened to, and addressed if possible:

> I get massages. I take my vacation when I need to take it. I have a very supportive partner thankfully, who does a lot to help out. And I talk to my colleagues. I have a good relationship with a lot of the nurses here and at team huddles, sometimes we do take a few minutes to reflect on certain situations and it's just everyone needs to express themselves, get it off their chest sometimes. But also, we need to have solutions and know that there's a way, a

[x] "Radical acceptance rests on letting go of the illusion of control and a willingness to notice and accept things as they are right now, without judging. It involves accepting that reality is what it is; accepting that the event or situation causing pain has a cause; and accepting life can be worth living even with painful events."[313]

> process to deal with it as well. It's not... It's not just to vent, it's to know that something, there's going to be action taken.

Although she doesn't consider herself religious Eleanor acknowledges how some of her colleagues are helped by their faith:

> I do worry about some of my colleagues if they don't have the support at home or they have other issues going on in their life. I can't imagine how distressing some of the work could be here, or how mentally difficult that can be, but I think a lot of my colleagues do have a strong faith and that helps them. That's not something that I relate to, but I do understand the strength in that and the importance of that.

4.9.1.2. Moral Distress in Relation to - & Emotions

Eleanor is asked if she has witnessed HCPs giving false hope to a patient or family. She immediately shares an example, also shared by many of the other participants, of a case involving the physician who no longer works on the unit:

> So, there is one incident that took place that stuck with me. One of our ventilator patients who received a prognosis at another healthcare facility, a very guarded prognosis, that she would likely not regain neurological function because she had been in her condition for, I guess, about a year at that point. And the physician was optimistic but telling her she would walk again; she would be able to get off the ventilator. She would be able to eat again. So far, none of those things have happened. The patient actually declined from being off the ventilator, had a significant cardiac event as a result of desaturating from being off the ventilator, and it causing too much stress on her body. So having to be the nurse in that situation was very stressful and knowing that she probably wouldn't reach those goals that the physician had told her, was upsetting for the patient, but also for the staff, including myself, knowing that it likely wasn't going to be the reality.

I inquire as to what feelings this situation evoked in Eleanor:

> Frustration. Helplessness. Sort of being silenced in a way. Not that it's my job to give a diagnosis or a prognosis but knowing something isn't accurate and not being able to say anything, sort of having to go along with it because it doesn't, the team doesn't, seem united if the doctor says one thing and the nurses say that's not going to happen. So, it's just a feeling of frustration and helplessness.

It is vitally important that processes are in place for staff to be able to feel safe in speaking out when they believe the treatment is no longer appropriate. Eleanor's

helplessness, in the face of her belief that she was unable to say anything, could have been alleviated with a request for an ethics consultation. I ask Eleanor how she feels now the case is resolved and the physician has left:

> I feel like it's done some damage to the patient because they still haven't come to terms with their prognosis. So, it's very difficult to see that person, who is given false hope not able to properly grieve their current situation and I feel like it's really difficult for the staff as well as the patient, but it's, it's hard to accept. It's hard to navigate communication with that patient. But trying to focus on the positives and not discuss that is easier than having that conversation with the patient.

Avoidance of discussing with the patient any related topics and an inability to accept what happened are understandable given these circumstances. It is vital that staff are given the opportunity to debrief and reflect on these particularly challenging experiences so they may forgive, accept, and heal.

Eleanor discusses another case where a patient's prior expressed care directions were not followed by their family. This generated significant moral distress for Eleanor:

> There was one patient with ALS, so no cure. It progresses and worsens until the person can no longer eat, drink, move, speak. Has a total loss of control. The patient was wearing a BIPAP mask (similar to a CPAP). He didn't want a tracheostomy. He deteriorated and went to ICU, and he came back to us with a tracheostomy and on a ventilator. The patient could no longer speak for himself. I believe eventually the team had a family meeting and the family decided to opt for the vent' withdrawal, and it had been after a few years of the patient being on the ventilator. And at that point, the patient was very ill. He had other health issues that were causing him pain and suffering; so, it did resolve in the sense it just resolved after years of that patient living on a ventilator, unable to speak or direct his care and the family directing it for him.

What feelings did this generate in Eleanor? "A lot of frustration and sadness. Anger because it felt like the patient had expressed his wishes to his wife… If the husband explicitly told her it's not what he wanted then out of love and respect for him, she should have respected his wishes." I inquire if Eleanor has another particularly morally distressing case:

> We do have a patient, she's around my age, and she's been on a ventilator for about ten years now. They're not exactly sure of the diagnosis, specifically, just neurological. The patient is now locked in. So, she can't speak, she can't move.

> She can't even blink her eyes. She has a tracheostomy, on a ventilator, feeding tube, urinary catheter. We had a family meeting with the mother. The mother wants to continue with the ventilator treatment. After ten years of no improvement. If anything, the patient has declined. Has developed wounds, has higher risk of infection and has developed infections. The patient from being on the ventilator for so long developed a pneumothorax was treated with a chest tube. But seeing someone so young... That I guess putting myself in her shoes. She should be out living her life and enjoying her life, to see her trapped on a ventilator in the same room every day. The family doesn't want her to get up in a wheelchair, so she's in bed 24/7 every day unable to communicate in any way. It just seems inhumane to me.

I suspect that this would seem inhumane to many people. Eleanor's moral distress appears more pronounced because of the similarities in age and the identification she feels with the young lady, "trapped on a ventilator in the same room every day."

What is the right thing to do in this situation? Is it ethical to "encourage" the mother to consider letting go; to speak of the suffering and pain of her daughter's continuing treatment. Is the SDM acting in the best interests of the patient? What is the threshold for a referral to the Consent and Capacity Board?[y] I ask Eleanor what could be done in this situation. "There would be a potential solution if there was some sort of Ethics Committee that is completely disconnected from the patient care, so an unbiased group of people that would be able to review the case objectively and maybe offer suggestion." I am unaware if the Ethics Consultation Service has previously been involved with this case. This service is available in the hospital and most other hospitals in Canada. It is unfortunate that many staff are either unaware of its existence or lack the ability to reach out to the Ethics Consultation Service. One of the recommendations forwarded in Chapter Five will be improving all HCPs knowledge of, and access to, the Ethics Service. Eleanor goes on to say:

> I do think in extreme circumstances such as this one, it could be beneficial to have some sort of external ethics group, or even just offer support to the family to maybe make them understand better what the reality of the situation is; because the family clearly is not able to grieve if they don't accept the reality of

[y] "The Consent and Capacity Board is a quasi-judicial administrative tribunal which operates at arm's length from the Ministry of Health under the authority of the *Health Care Consent Act.* The Board operates at the intersection of health and justice with a mission to provide timely, fair and accessible adjudication of issues relating primarily to matters of consent, capacity and civil detention impacting vulnerable Ontarians. The Board adjudicates on a broad range of issues including substitute decision making and end-of-life care."[314]

> the situation, which is also distressing, not like dealing with the family member, also causes distress, knowing that they don't accept it.

I inquire as to whether Eleanor has seen a similar case resolved satisfactorily:

> To be honest, I have not seen any resolution that I would consider satisfactory. I think usually the situations that I've seen personally, it's taken years for the family to accept… There is one situation another young man in his 30s, on a ventilator, locked in. When his mother finally passed away, after over ten years of being on a ventilator, the other family members decided for ventilator withdrawal, and they said it was because their mother couldn't bear to do that to her son. But all the sisters of the patient knew he wasn't going to get better, and they didn't like… Maybe they weren't comfortable with her decisions. But they had to wait until she passed away to do the ventilator withdrawal.

Eleanor recounts another couple of cases that she found very stressful and frustrating. In one she felt the doctor was trying to please the family instead of having a difficult conversation with the family about the reality of the situation based on the opinions of many HCPs. She describes one patient with stage four cancer totally dependent for care who was sent to acute care and managed there. The patient returned with a recommendation from the acute care team that they should be palliative and that they only had a certain amount of time left. However, when the patient returned to the unit the physician changed the code status back to medical and transfer and was actively treating the patient. “One of the patients was still having vital signs, antibiotics, chest X-rays, blood work… One of them actually went out for a bone scan which given the prognosis… seemed unnecessary to me and painful… that was very stressful and frustrating.”

I ask Eleanor what it feels like when one experiences these types of cases repetitively:

> There was a lot of sentiment, especially during the pandemic, that the hospital maybe didn't care about the nurses as much as they said they did. Yeah, just feeling like a separate part, separate from the rest of the hospital, or like our input wasn't valued, or the physicians weren't maybe doing their role, or could have done better. Just frustration.

We move on to discuss if Eleanor has had to follow a physician or family's request not to discuss a patient's prognosis with the patient or family. “It has happened where families want to withhold certain bits of information to patients and just being aware of

that is uncomfortable. It feels dishonest. Doesn't feel respectful to the patient." How would she deal with the family who wanted to withhold information from the patient:

> If I was still at bedside, I would probably discuss with the manager. I just remembered one situation actually with one young patient who the family member kept telling her they were going to take her home and she was only here temporarily. But then the family member would tell the nursing staff, 'don't tell her she's not coming home. This is her permanent home.' That's one example of a situation that felt like we were withholding information from the patient and the information was pertaining to their life, so it didn't feel good to have to withhold information from someone that had to do with the future of their life and their situation.

Some have argued that denying information to a competent patient is a violation of the doctor's role as a fiduciary and is never acceptable.[315] Other authors believe that the therapeutic privilege allows physicians to be discerning with what information is given to the patient if the disclosure would be so upsetting to the patient they could no longer partake in a discussion about therapeutic choices and consequences.[316] When is too much information too much? There is a significant body of literature around the concept of informed consent that struggles to answer this question.[317] The physician must also be mindful of the nocebo effect, whereby negative expectations flowing from a clinical encounter can yield negative outcomes.[318] Studies have shown how the nocebo effect is indicative of how information disclosure such as potential side effects may result in producing adverse effects.[318]

4.9.1.3. Dealing with & Healing from Moral Distress

Previously when we were discussing the case of the young female patient that Eleanor had identified with, I had asked if there could have been a timelier solution. Eleanor had stated that… "there would be a potential solution if there was some sort of Ethics Committee that is completely disconnected from the patient care." Later I asked her, in the previous eight years of her time on the long-term ventilation unit, how many ethics consults had she been involved with. "I've only heard of one ethics consult. Working at the bedside I'm not sure I was privy to that information. Now that I'm the assistant manager I feel more in the loop with the communication and the family dynamic side of patient care." She then goes on to highlight how nurses at the bedside may not have full up-to-date knowledge of the patient's treatment plan, which can exacerbate moral

distress. “As a nurse at the bedside, it's really focusing on the task at hand… Sometimes the family politics is left to the social worker and the manager and the nurses, we're not always kept up to date with that.”

Interested, I inquire as to the case that was referred to Ethics:

> It was a patient with ALS who was losing his ability to swallow, but he was refusing to get a feeding tube put in. He had choked a number of times, turned blue, needed to be manually ventilated and to have his airway cleared. Which was very distressing for the staff because they were feeding him because he wanted to be fed; but feeling like they're going to cause either an aspiration pneumonia or cause him to choke and potentially die or face the consequences of choking, so there was an ethics consult on that.

These particular cases do result in significant moral and emotional distress for beside nurses, and I know there have been other similar consults to the Ethics Service from the long-term ventilation unit. Intellectually these cases often represent a values conflict between the nurses’ professional obligation to protect the patient from harm and their duty to respect the desires of the patient to eat.[319] Emotionally it is very distressing to the nurse, who feel that they are choking the patient when feeding them, and that their actions may directly lead to the patient’s death. I ask Eleanor if there's enough awareness in the hospital that we provide an ethics consultation service and if it is fully utilized. “I don't think it's used enough. I wasn't aware of it when I was at the bedside. I sort of assumed that unless the physician took the lead on that we would just proceed with the family and patient wishes, whether or not we agreed with it.”

Regarding the situation when Eleanor felt the physician was avoiding having a difficult conversation with the family, I ask what could be done to help:

> I think a family meeting with the interprofessional team and maybe a second physician or another physician to review if that physician was unable to have a difficult conversation with the family for whatever reason. For another physician to step in and explain to the family in a way that they would understand that this person's illness is only going to worsen. It's not going to improve. Say our recommendation is to make them comfortable rather than continue with aggressive medical treatments that could prolong suffering and cause pain.

The art of the difficult conversation is a skill that comes naturally to few and must be learnt and practiced by most. The challenge for a physician is that their time is limited

and their words must concisely and accurately extract and present information that will lead to decisions about technically complex and emotionally charged information.[320] Many physicians report that training in effective communication occurs mostly on the job, with inadequate supervision, and often with no ability to debrief.[320] There remains a lack of understanding of why some physicians seek improvement and how they may build their capabilities at the bedside.[321] I ask Eleanor how we can improve the way we deal with moral distress and its causes:

> I think listening to the frontline staff who spend the most time with the patients. To make them feel validated and valued for the work that they do and the knowledge that they have and for physicians to take that into account as well, and if a difficult conversation with a family member needs to be had to involve as many team members as necessary to effectively deliver that message so that the patient receives the best care. Because in the end if everyone is united in the patient's healthcare goals and how to best approach it, if we all come together to say this is the best way to reach those goals, then I think everyone would feel better about the situation.

> I think having team huddles with the nurses and with management is helpful. Team rounds with the doctors to discuss the situation, at least to know how the situation would be approached and the timeline that it would be approached. It's just helpful to have someone validate the stress that the nurses go through on a regular basis and to feel heard and to address the situation, to know that someone is addressing the situation, what steps are going to be taken.

What advice would Eleanor give to a colleague or new nurse in dealing with moral distress:

> I'd say talk to your colleagues, to talk it out with your colleagues and your nurses. If you have access to it, maybe talk to a counselor or a therapist, if it's really upsetting you. That it is important to talk to someone who understands. I think being in healthcare, the only other people who truly understand are other people working in healthcare. So sometimes talking to a friend or family member about the stresses of your day in the hospital, it doesn't always feel like they understand, or they have more questions and then it becomes not about supporting you. It becomes about answering their questions.

The paramount importance of peer-to-peer-support, and the healing provided in that identification, is once again highlighted by an HCP in this study and form part of the recommendations in Chapter Five. I ask Eleanor if she thinks a facilitated peer-to-peer support group could be helpful for nurses. "I think it could be really helpful to have

maybe a nurse with like a behaviour support nurse… who also is able to facilitate those conversations with other nurses."

I now ask Eleanor for her three wishes that she would want fulfilled, if in charge of the hospital:

> Of course, more resources. To have more allied health and more nurses. I know everyone has a heavy workload as it is, so having more staff for the patients, but also to ease the workload for each other would be beneficial. I think also having a psychologist or a counselor to speak with the nurses sometimes would be beneficial or… a peer group could be beneficial. I think that our communication overall, just so that the whole team is aware of what's being done or how a situation is going to proceed. Just so everyone can be on the same page and united in their approach and comforted that there will be a solution and there are steps being taken to resolve issues.
>
> The ethics board that exists here… we should use that resource more for difficult family dynamic situations with patients. Maybe just to have an unbiased opinion on how to proceed with certain situations… the nurses, may not be aware that they're able to access that, or if there's a way, they could initiate that process. With consent of the family, of course, and with the physician's approval.

If Eleanor was able to design her own long-term ventilation unit, what processes might she put in place for dealing with moral distress:

> I would put in a psychologist or counselor or a psychiatrist… someone for the families and the patients, but also one for the staff. I think a lot of the families have things they need support with that we don't have the capacity or the resources. We try to do our best with spiritual care and managers. We regularly have contact with certain family members, we reassure them. But to have a professional maybe sit down with that family, or as well with the staff to help them cope.

Eleanor, drawing on her experience as both a bedside nurse and the assistant manager on the long-term ventilation unit, provides some excellent suggestions for healing from and dealing with moral distress. She specifically highlights the importance of peer-to-peer support; the need to feel that you are being listened to and your concerns acted upon; increased awareness and use of the Ethics Service; and mental health support for patients and families. As a recent staff nurse caring for the ventilated patients

Eleanor's testimony provides depth and authenticity to these suggestions, which will be recommended in Chapter Five.

4.10. Physiotherapy

Physiotherapists are regulated HCPs who play a significant role on the unit caring for the long-term ventilated patients. "They work with the multidisciplinary team, and patients and their families, to assess, diagnose, and treat symptoms of illness, injury or disability and expedite discharge planning."[322] They provide specialized clinical expertise helping patients increase mobility, build muscle strength, restore and increase range of motion in joints, improve walking and balance, relieve pain, and optimize lung function.

The literature investigating moral distress in physiotherapy is sparse.[323] Historically moral distress was seen as a nursing issue with much of the research directed at nurses. However, physiotherapists are a vital and necessary component of the multidisciplinary team on the long-term ventilation unit and are actively involved in the ongoing rehabilitation and care of the patients. It is important that the perspective and lived experience of a physiotherapist working on the long-term ventilation unit is heard, to complement and inform this research study.

Physiotherapists may suffer intense emotions in relation to moral distress and workplace conflicts and constraints, with senior therapists despite higher self-efficacy and moral sensitivity, describing persistently high distress.[323] Quantitative results have revealed that women and paediatric physiotherapists may experience higher moral distress, positively correlating with moral sensitivity.[323] Significant burnout has also been recorded in physiotherapists resulting in challenges such as staff retention, effective patient care, and overall staff well-being.[324] Recognizing and addressing moral distress will be pivotal to mitigating its impact on the physiotherapists working on the long-term ventilation unit.

4.10.1. Joe - Physiotherapist

Joe has worked on the long-term ventilation unit for more than seven years and has significant experience with complex respiratory care patients.

4.10.1.1. Meaning & Faith (Resilience)

Joe was drawn towards physiotherapy through his interest in sports. His intention was to work in the sports field when he started physiotherapy, but he then discovered the hospital setting. He really enjoyed the teamwork aspect of hospital-based physiotherapy and… "working with people who are in great need of some services that I could offer. So, I found that to be a passion as taking someone who has a lot of problems and helping them a little bit with some of them, I found really fulfilling." I inquire if the population on the long-term ventilation unit is different from the sports population. "Yeah, it's very different, and I've sort of felt like there was a lot of risk management involved in doing physiotherapy with people who are so complex, and I really liked that myself."

What are Joes's favourite parts of his work on the long-term ventilation unit? "The favourite part would be… the moments of human connection that develop here. If someone who has a communication deficit manages to get the message through and I can be the one person to hear that." His least favourite parts of the job speak to the complexity and bureaucracy of the modern-day hospital. Bloated bureaucracy is seen in many businesses resulting from friction, insularity, disempowerment, risk aversion, inertia, and politicking.[325] Solutions for healthcare that have been successfully implemented in some organizations include structuring leadership systems to connect everyone in the workplace to the issues that those staff toiling at the coal face are confronting every day; prudently outlining the roles of each level of leadership to include supporting the speedy resolution of issues on the frontlines and encouraging juniors to engage also; and designing and vigorously managing their operative systems.[326] Joe goes on to say:

> I'd say the least favourite part is all the coordination it takes to get a seemingly simple task done. So, for example, for a patient to see me in the physio' gym, it takes the day before having documented that there's an appointment time, the nurse coordinating with their PCA or their colleague that there's an appointment, getting that person ready, for that person's care going smoothly enough that they're up in the chair at that time, the porter's available, if the porter goes to get them and the porter brings them. It's just a lot of things that have to go right for what outside of here could be a pretty simple thing. So that's really frustrating when if someone has to use the bathroom five minutes before

> their therapy time, that's going to take all of the therapy, and we've missed that opportunity. That's part of something that's frustrating or least favourite I should say.

I now inquire what Joe's understanding of moral distress is:

> So, I find it's when there's a sharp difference between what someone wants or expects or hopes for, and what the evidence would suggest is possible and the confrontation of those two. It seems that those two things can't live together. The confrontation of those two things and coming to terms with that difference.

I ask Joe if moral distress would be different from emotional distress or an emotionally distressing situation. "I guess it would be. I know some would use the word should. But ethically what would be the best, most in line with the values of the institution, of the society, or the person. Would be the moral aspect of it." What does that actually feel like, that confrontation to use Joes' phrase. His visceral words speak volumes:

> It feels like a sinking feeling in my stomach. When as a sympathetic person trying to communicate clearly as I can and in a way that will be received, and I think that there's a clash and that things need to be reconsidered. Sometimes throughout my career I have thought a lot about saying that I wish for people to know the truth and be upset about that, than to be content with something that's not true, and that my job is to convey the truth accurately in a way that is understood. I've noticed sometimes in my career where I've communicated something maybe with a little bit too much icing on the cake, and I don't know if the message was well received because of that. So, it's something I've been working on is trying to convey the truth. And if that is something that the person doesn't want to hear, that is my job. That's where my job is.

Joe is another HCP in this study who struggles to walk the line between honest, healthy, and helpful communication, and rationalizing one's choice of words in an attempt to not upset others, or cause confrontation. I suggest to Joe that this is a difficult skill to learn. "Yeah, it's been a good challenge, and I find that aspect fulfilling as well." Personally, how does Joe navigate these potentially morally distressing situations:

> I think on a personal level, you need to really reflect on what your values are and what you see your role in the hospital and the community as, and if you find that your values align with what you're being asked to do. I would say if you have reflected and you understand what your values are and can be conscious of them, even if the actions that you're being asked to carry out don't match with those values, that you're being mindful of the values that you set for yourself as a professional in your career.

I am reminded of the Buddhist Noble Eight-fold Path when hearing Joe articulate his personal morality and practice, particularly Right understanding, Right thought, Right speech, Right effort, and Right mindfulness.[327] I tell Joe I believe that he is a man of principle who strives to be truthful. He is living Steps Four and Five, honesty and courage. I ask him what emotions are generated when he is placed in a situation where expressing the truth becomes difficult:

> I'm not sure I could say the one word to describe the emotions, but I'll describe it. It feels like you're kind of just being a cheap version of the person you want to be like. So, I think my mom is someone who can't lie, so I would always use whatever strategy she used to communicate with these people. So, for example, when I was a kid, I'd say, 'Mom, does Santa Claus exist?' She'd say, 'many people believe Santa Claus exists.' So, I'd always think of that when it comes to communicating with people, where we're not meant to share their prognosis with them or, which I always felt like in principle you are lying, because you're not being truthful, but within yourself, you're doing what you think is the least bad thing. Which felt like I was just trying but not trying as hard as I should or taking the easy way out.

It would seem that in those situations Joe believes himself to be inauthentic. "The notion of authenticity, i.e., being 'genuine,' 'real,' or 'true to oneself,' is sometimes held as critical to a person's autonomy, so that inauthenticity prevents the person from making autonomous decisions or leading an autonomous life."[328(p361)] Authenticity flows from living an honest and principled life and is necessary for successfully navigating moral distress in healthcare. Joe touches on what many clinical ethicists might often regard as the path forward for solutions to moral dilemmas in healthcare, namely the least bad outcome for all parties. Joe offers his thoughts on potential solutions to these conflicts:

> In this hospital, country, we try not to impose our values on anyone else. So, because of that, I don't think there's a solution because I'm sure people have their reasons for making those requests that are valid and based on deep reflections, thoughts and what they think is best for their family member or themselves… Even if I don't personally agree with it, I feel it's my job to be a supportive clinician.

I ask Joe if he considers himself a religious and/or spiritual person. "Oh, I would say spiritual person. Yeah." What does that mean to Joe? "I think it just means having a set of values to live by that aren't self-fulfilling, but in line with the, how to say this. This is a tough question." It is a profoundly difficult question; one that I carefully attempted to

avoid trying to answer as the researcher. Joe says… “My existence in this world. It's small compared to the universe, compared to whatever the greater powers are, and my role within this giant universe is just to help people and to be as helpful as possible.” That is as good an explanation as I could attempt. How does Joe’s spirituality help him deal with moral distress:

> I think it's helped because I try to break down each episode of moral distress to what can I do about it? What is within my circle of control? What should I do? What would the highest version of myself do? Whether that's really realistic or not and work backwards and I would say that spirituality has sort of guided my decision making and management of each episode I come across.

Finally, I ask Joe considering everything we've discussed during our interview what, right now, would be his definition of moral distress:

> Maybe it's just sort of like, one of the beautiful imperfections that make being human, being human. Like that life isn't perfect. That people have problems that we can only hope to help or that we can only hope to make more manageable. It's sort of one of the reasons that life's worth living because it's not always perfect and it's never going to be completely perfect, but it's not always good, I should say. Moral distress is something that encompasses this occupation and this setting, and it's one of the reasons I really take part in it… It's interesting, it's fulfilling, it's meaningful, it's challenging, and it helps build character and build life experience, I think.

So, like Frankl, finding meaning in suffering I opine. “Yeah. Yeah, well said.” Practicing the principles of the 12 Steps on a daily basis eventually gives meaning to the alcoholic’s suffering, while at the same time allowing him to gradually suffer less. Practicing those principles found in 12 Step spirituality, such as acceptance (Step One), self-honesty (Step Four), and courage (Step Five), may also bring meaning to the HCP’s moral suffering.

4.10.1.2. Moral Distress in Relation to - & Emotions

Has Joe witnessed HCPs giving false hope to a patient or a family? He says not, and then intriguingly offers an example of what he sees as a similar concept, namely when staff members accept patients’ expectations that are false:

> Someone who wanted to discharge themselves home against medical advice and would get certain team members to do things to facilitate that discharge, to

> make it safer. But the underlying message was that no matter what is done it's going to be unsafe, it's going to be dangerous, it's going to lead to serious consequences, whether we manage all of these things. So, for example the therapist was working on a kitchen assessment, but the ability to cook for themselves wasn't the problem, it was their respiratory status and their fragility.

What feelings did that situation generate? “Frustration, because we weren't and didn't feel like a unified message… that may give the person a false belief that they are going to be safe once they get home. I thought that was unfair.”

Joe had answered on the MMD-HP questionnaire that he had seen staff follow a patient's insistence to continue aggressive treatment, even though he believed it was not in their best interest. “Yeah, and I've seen people fight and suffer in circumstances that I can never imagine… I can remember someone saying, ‘you don't know what it's like to be in my shoes,’ which obviously I do not.” He then alludes to the importance of clear expectations from the treatment team and I can almost hear him asking himself, “why are we doing this?”

> These people who have had things, bad news after bad news, and any circumstances that I thought were bad have gotten worse. And they still insist on trying to do everything to prolong their life with the belief that they're going to recover. When the message hasn't been, that's unlikely to be the case and that from what I'm witnessing, it seems like the suffering is getting worse and prolonged through these measures.

He further articulates his confusion at some patients’ choices. “The will to continue down a path that is just more suffering and of a longer duration, I know it's kind of hard to deal with… if you haven't left a bed, and I just don't understand how someone, either themselves or their family, can look at that as quality of life.” I inquire as to what these situations feel like for him. “Disbelief. Like I question the reality of my lived reality and their lived reality. Despite the fact that we share this space 40 hours a week, every week, we have completely different lives. I wouldn't say I ever felt like I wanted to change it.” He further articulates:

> I definitely sometimes have a sense of fear, as in, what if I'm in that situation? What if my family member is in that situation? I don't know how they've made the decisions that they've made. Would I make the same decisions in that case? Maybe I'm pretty conscious that I'm looking at it from the outside objectively and I have a limited amount of knowledge on what their situation is.

> So, I fear that if I had all of the information, I would have made the same decisions as them. And how would that affect my family or myself in the future if I would ever be in that situation?

Has Joe ever felt pressured to carry out orders for what he considers to be unnecessary or inappropriate tests or treatments? It is enlightening to get a bedside physiotherapist's perspective to this question:

> Yeah, this happens in two ways. Not often. One is when I get a referral for chest physio' for someone who's clearly not a candidate for this kind of therapy and is clearly at the very end of life… they're ordering a difficult treatment that's uncomfortable and that can help, and I find chest physio' a bit... the scope not very wide because there's a certain population that it works really well for and a certain population it's just really uncomfortable for. So, I've had sometimes where people are insistent on getting chest physio', but I think they're clearly very sick and they're clearly at the end of their life. And it's like... you don't need to go through this.
>
> The other thing I see is when people are very medically complex but still want to improve their physical function. So, for example, we have some patients who want to be able to sit up on their own and transfer from the bed to the chair, but they are ventilator dependent, and it's explained to them that we can work on those goals, but that will not increase your independence in anyway. To which they 'say, well, we'll figure that out.' That's not how it works… There are times when they're very sick, but they still want to participate because they need to get better. But it's like you can take days off. I take a day off when I'm sick. You can take this day to just be sick and recover. I find that sometimes really distressing because one of my practice principles is that I'll do what the patient wants to do. So, I find that confrontation kind of challenging when it's like, I can see that you are suffering, but you're still trying really hard. 'Do you want to stop?' And they say 'no.' I think, okay, I'll try some more. And so, there's been times to manage that where I scaled back so that there was something being done, rather than nothing.

Using one of Joe's own examples, I ask him what feelings come up when he is providing chest physiotherapy[Z] on a patient which he believes is unnecessary and causing them to suffer. Like many of the HCPs in this research Joe shares the guilt and existential angst he feels in these situations. Does one feel guilt in these cases because

[Z] "Chest physical therapy (CPT) utilizes mechanical methods, specifically chest percussion, postural drainage, and vibration, to assist in airway clearance of lung secretions. Airway clearance techniques (ACTs) are critical in managing respiratory conditions characterized by mucus hypersecretion and impaired clearance, such as cystic fibrosis, chronic obstructive pulmonary disease (COPD), and various neuromuscular disorders."[329]

they did something wrong, or because they think they did something wrong? If I do not have all the facts of the case, I may feel guilt; guilt that may not be present when I am fully informed:

> Guilt. Feels like I'm doing something that I shouldn't be doing. I have some moments, and I remember some vivid thoughts from these moments, when I thought, what am I? What is my job? It's sort of like an existential thought, as in, what have I signed myself up to do? This is not what I should be doing. This is not fulfilling. This is not the career that I wanted... and I also just feel really bad for the patient, but that like, they just want to be helped, and I can't help them, or I don't think I can help them in a way that would be meaningful to them… It must be so scary for someone who's so desperate for help and can't find it. I think that would be a really hard situation. I feel really bad for the patients.

We talk about the utilization of finite resources in Joe's work on the long-term ventilation unit. "There are patients here who have very limited function… but demand a lot of attention through their requests… there's no potential for recovery, but yet they demand a lot of resources." Joe further discusses the nature of autonomy in his role. Autonomy in one's work is typically seen as a positive attribute, yet Joe highlights the flip side, when a lack of guidance and protocol may place pressure on the HCP. "I find that very difficult… when my job has very little guidelines on how I organize my day, and I sort of just decide all of that on my own. So, when someone with a poor prognosis is demanding more resources… I find that very difficult to manage, and I'm very distressed." I inquire what this feels like to Joe. "I guess anger at times, but we offer a service that is publicly funded. And yet people often ask for more… sometimes I feel misunderstood too. I think people don't understand… that my job is to help them, not to cheer them."

As our conversation progresses Joe uses the term compassion fatigue, one of the few HCPs in the study to specifically use this phrase:

> I think, I guess a sense of sometimes compassion fatigue with people who want to pursue things that aren't evidence based. I know they're not doing it in a way that is selfish or greedy or impulsive. It's a well thought out request that they've made but I just feel there's nothing I can, even if we did what you're asking to do, you're not going to be able to walk or transfer to your chair. And it's just very tiring from a compassion standpoint.

Compassion fatigue is a phenomenon borrowed by nursing from psychotherapy, and though its origins were in crisis counseling, it has evolved into a contemporary synonym for any HCP stress.[330] Compassion fatigue is defined as… "psychological, physical, social, and spiritual exhaustion with decreased power and desire to provide care to individuals as a result of the continuous and intense care given with compassion and empathy in healthcare professionals."[331(p104)] Compassion fatigue and moral distress are synonymous phenomena and high compassion fatigue may impair moral resilience, thus aggravating moral distress.[332] However the term appears to be falling out of favour in the healthcare literature with some authors now arguing it should be critically re-evaluated to support a new conversation on HCP work-related stress.[330]

Joe was working on the unit before, during, and after the pandemic. Though this study was not specifically about moral distress during the pandemic it was a significant factor for all the participants. I am very interested in Joe's lived experience during COVID-19:

> I remember when we were in September of 2020 with a big Covid lockdown, there is a big staff shortage. And I was off to myself for a bit in isolation, but then I came back to a severe staffing shortage, and it was quite murky. I remember those days quite vividly because it felt like an alternate reality, a different universe, and there was so much shortages. So many, so much scaling back of care that had to be done because of that. And I remember those days quite a bit.
>
> So, when Covid started, I remember one of the first things that happened here was we increased the number of ventilated patients that we had… So, moving a lot of patients and getting to know new patients and then everything shut down and then nothing happened… Everybody else was working from home. Nobody was coming to visit patients, and everybody was just waiting that summer for Covid to happen in the hospital, and that summer nothing happened. And I just remember it being very eerie that no one could come visit because Covid was going to strike in the hospital at any moment and for months it didn't and so patients couldn't see their families. We were helping coordinate video calls for patients and families.
>
> Personally, it was a very weird time because my partner was working at home and not seeing anyone, and I was working here in the daytime and talking to people all day about what they would normally talk about with their families and their visitors. So that was quite a difficult dichotomy where I wouldn't want to talk at all in the evenings. My partner would really want to talk, so that was kind of weird. And then summer went off. And then in September was when the first patient here was diagnosed with Covid. And then within days, half the staff were

> off, and eight patients had Covid. So, I was exposed, had to go into isolation. So that was weird because I was the only person in the allied health department to be in isolation. So, the people I had contact with were all at work and telling people how crazy it was that I was at home and not knowing what really was going on and sort of hearing rumours about this person's sick, this person's sick. When I came back to work, we were still in lockdown, and I only missed five workdays. But it was like the whole place had changed. And even some of my colleagues had learned all these new skills because of all the stuff that they had to do in those five days that I was missing. I was really impressed with how much my colleagues learned that they were showing me how to do some of the care aspects that they'd learned to do. I think it was my first time back working with patients who were Covid positive.
>
> Being really into sports, I was thinking about it as like my big-league moment, like we've talked about when Covid's going to happen and now it's happening. And we've talked, always done all these tests about infection control and getting to glove up, and gowned, what order, and how to handwash, like this is the time when you have to do it right. But it was always a test to try to get it right. And it was like, if I don't get it right, I'm going to get sick, or my family member will get sick. So, I think about that moment quite a bit. And then that sort of seemed to be the peak of it, of Covid in my life. After that, it always felt like as bad as that time was that we, we managed it relatively well. And from then on, I didn't have as much fear of Covid. After a sort of returning to normal, it sort of seamlessly, over months, went back to the way it was before. I just remember joking with some colleagues, like every time one rule would be peeled back, we would just joke about Covid's over. And then a couple of months later, another rule would be peeled back. And it just seems to have been as much changed in the world. Everybody sort of fell back into the way things were before. Which I think is nice. So that's sort of my experience here.

I ask Joe, if there was a similar pandemic tomorrow, what would he do differently. “I would not panic. I would not fear. What could happen because in my life, in society, people have always figured it out and have always been able to make the most out of any situation.” Joe displays a mature acceptance of the reality of life in healthcare. He goes on to use historical precedent to make sense of life’s unpredictable and cyclical nature. “It will be bad possibly, but it will be okay in the end. I think about how there's been natural disasters and terrorism and all the bad things that have happened, even war, that people resolve and continue their life.” I ask if we are prepared for the next pandemic. “No. But I'm not sure what that would look like either. I don't think anybody in the decision-making authorities will win votes or vote on... preparing for the next pandemic. I don't think it is what people want to hear. So, I don't think this is being done.”

I circle back to Joe's experience during the pandemic, of having a partner who was in the home whilst he was working in the hospital. What were the feelings at the end of his shift, going home after a day during COVID. "It felt like living in two worlds. Where here it was just like, well, no one was suffering from COVID itself, people were suffering because of COVID." Joe's words… "no one was suffering from COVID… people were suffering because of COVID," highlight the self-created suffering we implemented during the pandemic. Joe, with a sense of guilt, explains:

> People weren't able to see their family members. I felt so bad because at least I get to leave here, at least I get to go home, at least I get to ride my bike home. And these people don't get to see their families. They don't get to call them whenever they want. They don't get to hear their voice. They don't get to communicate. Sometimes there's one way communication with their family and their family can tell them about their day, which is they're not doing anything, they're at home. To going home myself where there was like this alternate media world that had risen through COVID about people making videos and cooking videos and sharing online platforms. I remember the one catch phrase was, 'we're going to be a... there's rainbows and everything's fine.' And I remember thinking, this is not how I am experiencing it. So, it's sort of like we were experiencing the pandemic very differently.
>
> I'm also a bit more introverted person at home and my partner's less. So I was kind of just being talked at when we would interact, or I wouldn't have anything to say. It was quite distressing for both of us, because neither of us were really getting what we wanted, or she wanted someone to talk to, and I wanted to not talk because I'd spent the whole day talking.

Joe had mentioned that the patients were unable to speak with or see their family members and he felt bad because he was going home. I inquire as to what exactly those bad feelings were:

> I'd say sadness, one. I remember saying a lot at the time that there's a lot of people who live here who maybe the one thing that they had to live for is seeing their family or visiting with their friends and stuff, and that's been taken away from them. I was really sad about that. I felt a little bit of guilt that I could be the one to leave and get away for a bit. Like these patients live in this environment. And there was no chance of things changing for months on end for them. I felt guilty that we couldn't provide something better for them and I guess sometimes I felt like I'm underqualified. But why would I? What would I do if these patients wanted to talk about something that I don't have, like the knowledge to have that kind of supportive conversation. There were some patients who really wanted to have deep personal conversations that I didn't feel like I have the training or the life experience to be a supportive person in those conversations

> and conversations that I'm trying to have otherwise with their families. I found that quite challenging.

Once again note the guilt and sadness of an HCP stemming from the implemented pandemic measures. Joe maturely reflects on feeling unprepared for providing the emotional and existential support that some patients needed as they attempted to live with the isolation and hopelessness they were experiencing. Joe also sees some positives that came through the pandemic. “There's a lot of things that I've learned through that experience of COVID, like clinically, personally, a lot, I learned about myself and what habits… I had developed that weren't healthy and what habits I can change.”

Joe and I discuss his experience with documentation. I was surprised to hear his perspective, which is quite different from that of most nurses:

> I find it kind of a reflective activity, because you're sort of revisiting everything that you've done in the day to document it. And then I find it quite simple. I find it doesn't put a big strain on my day. I don't find it takes up too much time and resources. I don't find I have trouble accessing the network and stuff. I find it a neutral part of my day… I also have the benefit of being able to look backdate my charting if ever I need to, and that hasn't been a problem for me.

I am interested if Joe recalls any one particularly morally traumatic event from his career so far:

> When I was a student here learning about one patient's traumatic experience, they had an anoxic brain injury from a suicide attempt, but I learned about the story of their life circumstances prior to their suicide attempt, prior to this massive anoxic brain injury… It's just not knowing what those feelings were, not knowing what those emotions were, not understanding that, like hearing their story and meeting that person just, like, completely consumed my thoughts for the weekend. I just remember being scared, knowing now, looking back, I know what those feelings were, and I'd be able to explain them now… I remember having a very distressing weekend because of not understanding those feelings and not knowing where they're coming from. It's sort of my first experience of really learning what someone's really traumatic life is... That moment is the reason I need to check in with myself and understand my own feelings and my own emotions because it can affect my behaviours. And I'm lucky that I just had a bad weekend and bad arguments with my partner. But those are emotions that I didn't know at the time. I think back to that weekend a lot.

Though this experience was very distressing for Joe, it is not moral distress. What Joe is likely describing is vicarious trauma and not moral distress. HCPs are at risk of developing vicarious trauma, which can result in adverse symptoms that often mimic PTSD.[333] Vicarious trauma is associated with mental, physical, and emotional issues for HCPs, including burnout and decreased self-worth.[333] Working on a long-term ventilation unit is intrinsically emotionally distressing at times, due to the death, suffering, vulnerability, and pain we are necessarily witness to. However, with the appropriate education and support we can help our HCPs identify, process, and heal from the various traumas they experience in their daily work on the long-term ventilation unit. To achieve this HCPs need the resources to be aware of the symptoms and available treatments, and management ought to support staff to decrease their workloads, encourage leave, increase supervision, and provide any necessary spiritual and mental health resources, as recommended in Chapter Five.[333]

4.10.1.3. Healing from & Dealing with Moral Distress

In those situations where family are pushing for continuous aggressive treatment, in a patient whom Joe feels is being caused harm, what processes might reduce the intensity, severity, or recurrent nature of moral distress? “I think that a lot of it is based on education and on what families and patients will understand… We only provide one avenue for education, for patients and families, whereas in the education system… modifications are made, so that people can learn.” As an educator I understand and see that people have different ways of learning. Joe makes this point… “I wonder if we are only providing one way of educating patients and families and some register the information they integrate into their decisions, where some patients and families seem to just ignore it or to not receive it at all.” Joe then offers a pertinent insight that… “by only providing one avenue we're only getting 80% of people to accept that education… these 20% it's not because they're ignorant, it's just because they don't learn in the same way that we teach.”

I inquire as to how the hospital could improve its response if there were another respiratory pandemic:

> I would say there should be one spokesperson for all the updates. One person or one representative of the department who does all the communication, because there's a lot of rumours normally in this institution that go around and when there's rumours plus multiple sources for different information, it's very misleading. Err not misleading... there is a lot of triaging of information that had to be done, which in turn made the decision making that much more difficult. I think of decision fatigue a lot when you have to decide what information you're going to take and then also decide how your actions are going to be. It's very tiring not making as effective decisions. I think if there was one message board, one department that said all the information, that would be what I'd like to see the next time, hopefully.

It is interesting that Joe raises this issue as I know the hospital did eventually implement such a system of communication during the pandemic. I ask Joe how he personally deals with and heals from moral distress. I note his use of meditation, which is part of Step Eleven in AA's 12 Step recovery program:

> I'm a pretty reflective person and I do a lot of active meditation called walking meditation… I walk without distraction or music or anything to really reflect on the things that I've learned about in the day, how they affect me. I try to talk a lot with co-workers here who have similar experiences and working with the same patients. And then another thing I do is I try to check the world that we live in here and the world outside of the institution and how those are compatible. I try to use a lot of metaphor and similes to equate experiences. For example, if you come in here and ask for more therapy appointments in a week, we have to say no because we don't have the resources, we don't have the time. But if I was in a private clinic, you would say no problem, because you just get paid so much more. And that's a good exchange. I try to reinforce the fact that I'm not turning somebody down. I'm just not giving them more than what they've been allocated to work with in that type of situation. So, I try to really stay grounded with what is possible and what people are allowed to ask. And we can say no. Yeah; I think there's times when I thought to myself why would they even ask that? Obviously, I can't do that. But then I think, well they probably were just asking because it costs nothing to ask.

What advice would Joe give to a student physiotherapist who was seeking support dealing with moral distress. "I would suggest doing a breakdown. Are they written or just in thoughts? Sometimes I like to write it down myself. What are all the components of the moral distress? What are the realities? What are the expectations? Where is that divide happening?" If Joe was given ten million dollars for dealing with and healing from moral distress in the hospital, what would he spend it on. "It should be used to hire the most amount of people as possible to make the clinical work less, but the work hours

the same, so that people have time to connect with patients and understand how they and their families made these decisions." In nursing and medicine this could be achieved through reducing the documentation burden, though in physiotherapy it is less clear. Joe further explains that… "There's been times when my workload has been very reasonable and how much more fulfilling the work was at that time because I wasn't worried about cutting people off, wasn't worried about getting to the next thing… So, I was a lot more relaxed." Indeed, for healthcare interactions to be truly healing and effective, the HCP must be calm and present. As Joe says… "I believe in modelling behaviour. So, when I'm more relaxed, the people I'm interacting with, they're more relaxed. There's a better understanding between people… We can have calm discussions… there's that much more time to do the deep-seated human connection."

Our knowledge of how physiotherapists are impacted by the demands of modern healthcare is limited. Joe's story adds depth and richness to the sparse body of literature studying moral distress in this population. Joe shares clearly how he is impacted by, and attempts to deal with, moral distress and its sequelae. He also provides wise suggestions, born from his personal experience, of how we might as a hospital and society deal with, and heal from, moral distress. Particularly relevant is his use of meditation, a fundamental component of Step Eleven in AA's 12 Step spirituality.

4.11. Spiritual & Religious Care

The spiritual care chaplains in hospital believe that… "spiritual care is essential to the well-being and healing of body, soul, mind and heart and see spirituality as a source of comfort, consolation, strength and hope for patients and their loved ones, in the midst of sickness, disability, loss and grief."[334] The chaplains on the long-term ventilation unit are sensitive to the cultural and religous backgrounds of the patients and families to whom they care for. However, in part due to the profound moral and emotional distress seen on the long-term ventilation unit, the chaplains are also vital to helping the HCPs on the unit deal with and heal from the distress and traumas they experience on a daily basis.

We know that chaplains working in palliative care, as opposed to those working in other clinical areas, appear moderately distressed.[335] There is emerging evidence indicating concerning prevalence rates of distress and attrition among chaplains, particularly since

the pandemic.[336] What of chaplains working on a long-term ventilation unit with a significant palliative care population? How do they deal with and heal from their own exposure to repetitive moral and emotional distress in patients, families, and HCPs? The literature on chaplains dealing with their own, and not others, moral distress is sparse, and Delilah's story shines a deeply meaningful, and at times painful, light on these issues.

4.11.1. Delilah - Unit Chaplain

Delilah has significant experience as a clinical chaplain, having spent over ten years in critical care and pediatrics, amongst other areas in acute care. She has spent the last decade caring for the patients, families, and staff living and working on the long-term ventilation unit.

4.11.1.1. Meaning & Faith (Resilience)

I share with Delilah that working with children in critical care and the emergency room must have been tough. She says that she quickly learnt to… "recognize, for example, working in pediatric resus and ICU that I cannot bubble wrap my kid. I'm gonna have a nervous breakdown if I worry about everything I've seen." Delilah shares a personal story and acknowledges that she… "was a mess at first. But otherwise, that work hasn't really, I haven't let it impact me, in a way it might have." I believe what Delilah is saying here is that she was able to deal with the vicarious traumatization that working with those populations inevitably generated. It is likely she went through an internal process as she tried to make sense out of the pain and tragedy of her early career. During this process of integration trauma-healers will often experience secondary traumatic stress reactions such as vicarious traumatization and burnout.[337]

What could a typical day on the long-term ventilation unit look like for Delilah:

> So particular to the vent unit, dealing with patients, struggling with anxiety, with decision making, with anger and frustration, with hurt. Helping them understand the meaning and helping them do the journey towards finding some sort of understanding or meaning, knowing that sometimes we never get there. Sometimes it's too difficult. Sometimes the family's too difficult, sometimes the system does not allow it. But doing our best to do that. Obviously, for people who have religious needs, connecting with them religiously, talking about a

> patient maybe who we could get a bird for, who loves birds and is dying. But that is a patient that's also very religious. And so, we kind of balance both meaning and religion together.
>
> I do staff support as well. I do debriefs when there have been critical incidents or if there's a vent withdrawal happening. We do a bit of a kind of a gathering before and a gathering after to process what's happened. Trying to think of what else. Staff support through Code Brew, which you aptly named, and generally ensuring that patients and families and staff are finding an equilibrium or peace wherever possible, not always possible, and then sitting with them in the tension of the not always possible and being okay with it, being okay with not being able to fix. That's a large part of spiritual care, which I think nurses would struggle with, which is acceptance of not being able to fix because in nursing you're trained to fix and to help and to comfort and when that's your goal and you can't do it, that's devastating. Whereas in spiritual care, we go in, we are trained, you cannot fix everything. Sometimes you have to sit in the mud on the muddy days.

Delilah is correct in that most nurses (and most other HCPs) often struggle with accepting reality when that reality is messy, painful, confusing, and there are no clear solutions. It takes a particular kind of healer, like Delilah, to be able to sit down in that and bear it compassionately without becoming overwhelmed themselves. I ask Delilah how she would articulate the concept of moral distress:

> Moral distress would be the sort of agony of defeat when you're facing very difficult moral situations, like do we continue this life, continue on like this, am I doing an indignity when I am caring for a patient this way, am I being given the right resources to safely care for them. Things like that. And the moral distress of I just can't seem to make a difference here. I can't seem to do what this patient needs me to do and the moral distress that comes with that too. But I think it's more being put in positions of not being able to do the kind of care that you've trained to do and expect to be able to do within a system that kind of sometimes goes down the wrong roads. And then you become distressed about how that did not feel like a good thing to do, that did not feel like a situation that I was comfortable in, which is why, again, we do the debriefs in order to let some of that come out, to talk about it. And if it is a bigger issue to try and get it addressed.

An astute and comprehensive conceptualization of moral distress. Delilah further shares how she experiences moral distress and pre-emptively mitigates it:

> So, it was a little weird for me because I'm not really put in situations of moral distress in the sense that as a chaplain, if I don't like something, I kind of go outside the lines and go to other people and say, ‘it's like this.’ Whereas a nurse

> can't do that so much, whereas an RT and a physio', who are all covered by Colleges. And it's the main reason I've chosen not to be a hybrid of a chaplain - psychotherapist, because I feel that would put me in moral distress, because I'm followed by a College then, and Colleges are not there to help patient centered care. They're there to police the people providing the care. And yes, there are instances where that's very important and necessary, but more often than not, it becomes a hindrance, I find. And so, it is why I've chosen I'm supervised by my manager, my director, and if I stepped out of line and do something wrong, I'd be out on my butt. But I made a deliberate choice not to be the hybrid of chaplain and psychotherapist like my colleagues, because it would severely put me in moments of moral distress, for sure.

This is a fascinating glimpse into how an HCP may deal with the reduced autonomy and control that could come through membership in a professional College. If we return to Jameton's classical definition, that moral distress arises when one knows what to do but cannot because of institutional constraints, then Delilah's rationale makes perfect sense. If she perceives that membership of a regulatory College would constrain her practice in the hospital, it would be an eminently pragmatic way of potentially preventing moral distress. As one of the fundamental characteristics of moral distress is powerlessness, then for Delilah having that sense of power, an increased ability to change situations not constrained by College regulations, would appear helpful. It is unclear just how much of this increased freedom would be real or perceived:

> Exactly and it's why I'm not joining the College of Psychotherapists. I won't do it. They're not there to help my patients. They're there to put a chokehold on what I do so that they can justify their existence too. How does that help anybody? Why not provide supports for all of us so that we can do our best work, but it's not the way our system works. There's such a need for power, there really is a need for power with people. And I find that that also causes a lot of moral distress. You know, the people who need power pushing their thumbs down on the people doing the frontline work, how does that help our patients? It doesn't. So, and then that causes the moral distress.

Delilah's differentiation and separation of powerlessness in some, and power in others, is a unique perspective in this study. The literature is replete with analysis of the HCP's powerlessness, and it make sense then that an appropriate transfer of organizational power "through the ranks" might result in less moral distress for those at the bedside. Delilah shares that thinking outside the box and being creative and innovative can improve the quality of life for our patients and families, and how she experiences moral distress when those with power… "are not letting me do what I know would improve

things.” This external constraint is not passively internalized as helplessness by Delilah, as is often the case with other less experienced, confident, or morally courageous HCPs. Moral courage may flow from workplaces with a positive ethical climate providing HCPs with the strength to probe work processes, and potentially leading to improvements in the health services they provide.[338,339] “It's why with Code Brew, I didn't ask permission before I started. I bought everything. I talked to the physician, and I said, ‘I have this idea’ And she's like, ‘here's the money. Do it.’ And then I told my director.” Those who have worked in healthcare for a period of time are often of the opinion that it is sometimes better to ask for forgiveness than permission.

Delilah was willing to take this risk because she knew how important and helpful it would be for the nurses. It held significant purpose and meaning for her:

> We have volunteers… who would have missed the point… yeah volunteers can push a coffee cart around and say, ‘hi,’ everything's surface though. Volunteers don't do what I did today with a nurse on another floor who when I asked how her day was, which was, ‘it’s all right, I'm going home. I'll see my parents this weekend.’ And I dug a little deeper and I said, ‘are you feeling overwhelmed?’ ‘Yeah, And I'm not sure how to handle that.’ And then I said, ‘you know, I'm always here to talk to you.’ And she said, ‘I'm not really like religious or spiritual.’ I said, ‘spirituality is not about religion per se. It is about your connection to meaning and feeling safe and purposeful in this world. And if you're not feeling that I'm your girl to talk to.’ So that's a lot deeper than a volunteer goes. And I have more training than a volunteer.

Deliah then emphasizes the importance of in the moment peer-to-peer support, and how she would have experienced moral distress if this project had been impeded:

> When we're talking about moral distress, staff weren't getting a lot of the talks that they needed in the moment because nurses process on the unit right in the midst of what's happening if they're overwhelmed or whatever. That's where it kind of hits them, right? Then they process in the car on the way home and then that's it. So, I would have felt moral distress if I had been told, ‘no, you can't support staff,’ because I'm sitting with them every day, walking with them every day, listening to them every day.

4.11.1.2. Moral Distress in Relation to - & Emotions

I ask Delilah if she has been involved when the family insist on continuing aggressive treatment, even though she believes it is not in the best interest of the patient. “I mean,

it creates moral distress for the staff. Yes, it upsets me, too. But I don't know if it's just because I'm old and I have the wisdom now or I can't control what they do. I can't. It's not great. It doesn't feel good." Delilah touches here on her acceptance of powerlessness in these situations, which has come with the wisdom of experience. Delilah now shares a distressing case which was also highlighted by one of the nurses:

> I think the most moral distress I felt was our patient who was end stage disease where the lungs shut down and decided they wanted a vent withdrawal and kept waking up after that withdrawal in distress. That upset me and it upset me because there's not a damn thing I could do about it, like to calm her and get her feeling better. It upset me because when we look at how we got there, another hospital, because it was easier to just make that person vent dependent, but they weren't ready to die, in terms of their lungs and body. And we weren't aware of that, and that was moral distress. I felt like not cool to send us that patient having made them vent dependent when they could have been weaned and had less stress… So, in terms of feeling like I was in a position that I shouldn't have been put in, that I felt like we were all put in a position we shouldn't have been put in with that patient. And our team worked together fantastically. It was the other hospital and the way they just dumped on us this big hot mess.

This research has shown how emotional distress is frequently confused and conflated with moral distress, and that they also often co-exist in the same experience. Witnessing this patient's pain and suffering results in significant emotional distress for Delilah possibly resulting in vicarious trauma. Though she was put in a frustrating, sad, and emotionally distressing situation, I do not see that Delilah was personally complicit or forced to do or say anything wrong. For it to be moral distress there must be a component of personal responsibility. In this situation there really was little, barring demanding more sedation, that Delilah could have done in the moment.

I return now to the contrast between helplessness and powerlessness. Is there a difference in these terms when HCPs speak of morally and emotionally distressing circumstances? Sometimes they are used to describe the same thing, yet I believe in some cases, the HCP is attempting to describe two distinct phenomena. Helplessness may be that feeling when one is frustrated, impeded, or it is simply impossible to make something better. You feel like a child watching two parents fight – scared, sad, and helpless. Powerlessness, when fully realized in Step One of 12 Step spirituality, can be the positive acceptance that accompanies growth. Alternatively, those feelings of

helplessness if internalized and given a justification story, stunt us and leave us stuck. This is not merely academic semantics, as how we conceptualize these events in healthcare will have a direct impact on our resilience and elasticity. Thus, changing our understanding and perception of these words, and how we use them, can shift our experience, coping mechanisms, and morality. Furthermore, by… "using the word 'powerless' to represent the situation and characteristics of the event, and the word 'helpless' to represent our internal and external reaction to an event,"[340] we might be able to provide the opportunity for the development of moral resilience. I ask Delilah what are the actual feelings that occur in these situations:

> Rage. Oh, good, Irish rage. My white-hot Irish temper. Yeah. Helplessness. Sadness for the patient and family having to endure that. Anger that I can't fix it, which I know I can't fix things. I understand that's not my role. But they're still there because it is such a, just an untenable moment in those ones. I really feel quite useless as a chaplain too, because it's just such a medical mess. And I mean, I came in after hours and spent time with the family and kind of, you know, I dealt with a family member of the patient, that was difficult, to support staff, but didn't feel like I was doing a lot of spiritual care per se. So that's when I get into moral distress, when I'm like, what am I going outside of my scope here? Or am I just like, getting in the way? That's when I feel moral distress.

I think what Delilah is describing here is not moral distress. It is emotional distress due to a sense of professional inadequacy. We move on to discuss if Delilah has been in situations where the team are continuing to provide aggressive treatment for a patient who is most likely to die, and no one will make a decision to withdraw treatment. Delilah recounts how she recently experienced this whilst her mum was an in-patient at an acute care hospital:

> I haven't experienced that here in terms of the teams doing it. I've experienced it personally with my mom at another hospital, which was horrific. And one of our doctors stepped in and tried to help and the doctor in acute care just rebuffed and kept like ignoring the fact that it's an 83-year-old who's ready to leave this world, had had enough, that the pain was too much, surgical interventions were overwhelming. And they still continued to push that. And I said, 'she's dying.' And they said, 'no she's not, she's drinking ginger ale?' And I was, 'are you familiar with the palliative performance scale? Like she's at about 20% right now.' And I wasn't listened to. And they kept trying to force treatment. It's all about money and it's not about the patient right.

Sadly, Delilah's story is all too common to those who have toiled on the front lines of healthcare awhile. Is Delilah's experience as both an HCP and a family member of a patient in hospital, different from a person who has no experience or understanding of working at the bedside? Surely it must, as coloured by our past experiences we don't see the world as it is, we see the world as we are.[341] Though there is a dearth of research on the experience of HCPs who are on the other side of the bed, as the loved one of a patient, we do have some understanding of the phenomenon. Four dominant ways of understanding the experience have been identified; the informed bystander, the supervisor, the advocate and the carer.[342] "The four ways of understanding this phenomenon are hierarchically related with 'the informed bystander' being least involved in the care of the family member and 'the carer' essentially taking over the patient's care because of unsafe, inappropriate, or poor care."[342(p50)] It would appear from Delilah's testimony she was fulfilling the role of the carer. As a fellow HCP who was aware of what can be missed in a hospital, when placed in a similar situation with my mum, I quickly and from my perspective quite rightly became the carer.

Delilah then shares a positive experience, when working with the team in the hospital in similar situations:

> I have never experienced our staff trying to push inappropriate treatments on patients and families here. I've experienced once where we didn't communicate well with a patient. So, it was a patient that had cancer and had a stroke… came here for rehab for three, four months, did the short-term rehab and recovered quite well, but had terminal cancer. So, in the meeting, the doctor said, 'you know, she's doing really well. I think we'll send her to the harder rehab,' and nobody was talking to the patient. I said, 'we need to have a better conversation.' That was not a good conversation and was not one that centered around the patient. It's the parents struggling to accept reality. It's the patient wanting something and nobody's listening to her. Assuming that… her brain is dead, but her brain wasn't dead, she was all there. So, we forced an honest conversation, whereas other hospitals sort of just skirted around it because the dad was like, 'oh, great, she's doing well. We're going to bring her in a longer-term rehab.' She just wanted to go home. She knew she was dying. She wanted to go home. And so, we facilitated that. Other hospitals don't always do that. So, in this hospital, to answer your question, I don't ever feel that. I have felt it, though, in other hospitals as a patient, family member, spouse, whatever.

Delilah's story speaks to the importance of having a true multidisciplinary team whose input and opinions are respected and listened to. I would recommend for this to work

the organization must have a culture of supporting and encouraging diverse perspectives and be comfortable when HCPs respectfully challenge the prevailing narrative. The HCPs must feel safe that they will not be marked out as “troublemakers” for their dissenting opinion. It does appear from the stories shared by multiple HCPs, including Delilah, that this hospital provides such an environment, and it will be recommended that this is nurtured and maintained.

I ask Delilah what does it feel like when the patient's family is pushing, and you don't think the patient would want this. “I do the best I can in terms of helping navigate that conversation… we had one who would put lemons under the bed saying it would make him better.” Once again Delilah displays a mature acceptance in these situations. “Well, I can't talk her out of that… I can't effect change there. So, my role then shifts to supporting the staff who are struggling with the indignities that they have to do.”

I inquire if Delilah has ever felt she is caring for patients or dealing with patients whom she didn't feel qualified to be caring for:

> Sure, I'm often sent to the psychiatric patients, and I'm not a psychologist or psychiatrist, nor do I wish to be. There is a special thing in spiritual care that I connect to deeply and that I enjoy doing, and that's way beyond it. Now, I will sit with the psychiatric patients who are struggling and listen to them. The staff often see me as like trying to fix all of that for them. I can't do that. And then I slip and try and support the staff because I know that they're struggling. But and I'll say, ‘this is out of my scope. This is not what the patient needs either. I appreciate that you trust me enough to try and make that referral, but I can't help with what's going on here. It's far too, way too far out of my scope.’

I sense the “special thing” Delilah connects to deeply in spiritual care is the identification of one human heart with another. Where psychiatry deals with the head, spiritual care deals with the heart. In 12 Step spirituality it is said that the longest 18 inch in the world is from the head to the heart. The 12 Step sponsor may suggest to a sponsee that instead of attempting to think their head into the heart, they instead bring their heart into their thinking.

There appears to be an increase in the number of patients displaying behavioural problems and also the severity of those problems over the last few decades.[227] Has that

been Delilah's experience, and does she have any idea why this issue is more prevalent:

> Totally. Our experience here at this hospital, we're the dumping ground for those people. Sorry, I call it 'Saint Elsewhere,' because this is where the bigger hospitals think they're all that and don't want to deal with that, even though they have psychiatry departments, dump them on us. Our healthcare system is not set up for psychiatry, for mental health support. It's just a mess. I did a rotation in psychiatry as a student chaplain. Some of the staff are just as damaged as the people that they're looking after. And there doesn't seem to be a political will to improve funding and staffing. And it's a mess because it's an icky thing that we don't like to deal with. And I think part of it is because we all have potentially in us mental health struggles, you know, how we deal with the world. But we've almost vilified mental health, right? We vilify cancer, but we can feel like heroes trying to fix it. Right? Nobody feels like a hero working with mental health. It's made to be something icky and gross. I had that experience. My daughter was diagnosed with an eating disorder. Boy did people get weird with us after that. You know, oh, that's a mental health thing. There's something wrong with her. If my daughter had been diagnosed with cancer, oh my God I would have had a whole community surrounding me trying to help me, supporting me, making me meals doing this, doing that. But no, it was mental health. So, oh stay away. So, I think it's societal. Societal, it's a lack of political will. It's mental or healthcare professionals who think they're too good for that kind of thing and then dump them down to us. And then our staff are not trained for that. We do not have psychiatric nurses on staff. We do not even have a psychiatrist. We should hire a couple of psychiatrists who do GP work as well as psychiatry and or train some students at the medical school level and say, 'look, we need GP's who specialize in psychiatry and we will work out like a salary or schedule or whatever,' but like recruit them early on and groom them to be here, you know, then maybe we have a hope in hell of at least keeping our staff safe, keeping our other patients safe, and keeping our psychiatric patients from feeling like they're spinning out in a big black hole.

Delilah's observation that "some of the staff are just as damaged as the people they are looking after" is an oft repeated trope regarding mental healthcare workers, alongside the meta-narrative of the wounded healer.[343] However, there are some truths to these stereotypes. In fact, the idea that psychotherapy is a haven for the psychologically damaged is as old as the profession itself. Freud himself believed that childhood loss was the triggering cause of an adult's desire to help others, and his daughter, Anna, also a psychoanalyst, wrote that the most sophisticated defense mechanism she ever encountered was becoming a psychotherapist.[344] Research suggests that physicians have high rates of mental health issues, including depression, anxiety, substance

abuse, emotional exhaustion, and suicide attempts.[345] Studies looking at childhood families of origin in mental health workers show that therapists are often raised in dysfunctional families and experience significant psychological distress in adult life.[346] Female mental health professionals, when compared to women in other professions, report… "higher rates of physical abuse, sexual molestation, parental alcoholism, psychiatric hospitalization of a parent, death of a family member, and greater family dysfunction in their families of origin than did other professionals."[346(p83)] What is interesting in Elliot's study is that as adults the psychotherapists… "experienced less anxiety, depression, dissociation, sleep disturbance, and impairment in interpersonal relationships than did women in professions other than mental health."[346(p83)] Three-quarters of the therapists in the study had received treatment themselves suggesting a willingness to examine the causes of their distress, which may have led to their reported healing of their childhood trauma. In 12 Step spirituality a willingness to change is a fundamental prerequisite for recovery and healing. The Big Book of AA, what some may call the bible of 12 Step spirituality, implicitly states that the essential "HOW" of recovery is honesty, open-mindedness, and willingness.[5]

I ask Delilah if she has participated in care that's caused unnecessary suffering or been involved when a patient has not received adequate pain relief. She shares an experience of when she was a new chaplain in the hospital:

> When I first started here, there was a patient not getting adequate pain relief, and the doctor that was here said, 'well, it's not my patient.' And I said, 'right but the doctor whose patient it is isn't here, and you are.' He went off on me and he complained about me. Ultimately he was told, 'why don't you just give the patient the damn pain meds, like you were on site.' This other doctor wasn't coming in for another two days. You can't leave a patient suffering for two days. That was hard. I was a new chaplain too. Now I would just go straight to senior leadership and go, 'the Doc is not relieving this patient's suffering.' But that was as a new chaplain here, that was rough, rough. Yeah, because they called me in to do spiritual care. And I said, 'I don't have magic pixie dust. This patient has actual physical pain.' You know, until we mitigate that or at least try to do better, I can't come in and do spiritual care. This is why they can't focus because they're in so much pain, you know. So that was that was morally injurious, if we want to call it that.

Delilah uses the term morally injurious here to express just how painful this experience was for her. The fact that she still feels the impact of that experience would signify that it

has indeed crossed the threshold from moral distress to moral injury. Furthermore, when I ask her if she had to choose one particular traumatic event from her career she instantly replies… “that one...that one. I really could not believe that we were going to leave this patient in pain. I was furious and I was so annoyed.” She tells of another case of an 89-year-old patient with significant illness. It was the same treating physician, who is no longer at the hospital. The patient died suddenly, and the family in their search for a meaning requested an autopsy. Delilah counselled the family and they decided against, what they felt would be an indignity, of an autopsy. However, the physician had wanted to do the autopsy. “I said to him they don't want it now… I talked to them, and we recognize that they're seeking meaning that has already been in front of them the whole time. He was horrified and says he would have done it.” I inquire as to what specific feelings these cases generate:

> Anger, frustration, helplessness, fear for the patient and the family. Fear that the place that I love working in is going to look like ass holes… You're not allowing them to move forward in grief, which they need to be able to. You're going to allow an indignity that is unnecessary. It's not like he was walking down the street and dropped dead for nothing… So yeah, messy. I was like, gosh, how can you be so stupid? It's anger and fear and moral indignation and all of it. I hope it doesn't sound arrogant because I don't think I know better than him. I just recognize because I've been accompanying this family, they're struggling to find meaning. This isn't how you find meaning. They already know what he has. All the diagnostic tests have been done.

Once again, a participant applies the terms helpless and anger together when describing the specifics of a case. Anger, as long as it is not expressed physically, is oftentimes an appropriate and healthy emotion.[347] The issue with Delilah’s anger is that she may not actually be experiencing anger, what she is likely experiencing is rage, “hot Irish rage” as she referred to it. Rage is an unhealthy emotion, because rage equals anger plus helplessness.[348] It is the sense of helplessness that needs to be corrected to restore equanimity, through shifting one’s attention to the helplessness they are feeling. One simple antidote to alleviating the feeling of helplessness is to take some form of positive action.[348] If the HCP can find the moral courage, and ideally they work in a morally encouraging organization, just one small word or action can change how they are feeling and engender a sense of empowerment. In 12 Step spirituality you’re advised to feel the feeling, share the feeling, then look to help another person.[7]

We now move on to Delilah's experience of the pandemic. Delilah was working throughout the hospital and also covering the long-term ventilation unit during this time. Due to staff shortages, she was the only Chaplain at the hospital. Furthermore, she was trying to care for her mum whose health was failing and who eventually became palliative. I ask Delilah what it was like:

> Shit show! That's what that was. An unmitigated shit show and terrifying and fearful. And in the midst of that, dealing with a dying at the time, 81-year-old mother, and trying to make sure she didn't die alone. Because remember, at the beginning we thought we were all going to give it to each other and kill each other. Right. So having to stay away from her, having to deal with patients and families, well families couldn't come in, having to be part of those discussions on that Sunday. And I remember one of the senior leadership team looking surprised that I was here. And I'm like, 'we're about to tell people they can't see their family members. That's not going to go well. Like, you need somebody who's not the boss to cushion that,' and they really couldn't see it. That's a moral, a scary thing, that I saw go down in terms of the power that healthcare kind of revelled in during that. That for me was a moral injury. But going home, afraid, coming into work, afraid, you know, going into COVID patient rooms. I was 55 I think at the time, or 54, with diabetes, overweight going, oh, I'm like the prime target for this. Am I willing to put it on the line for this or do I walk away from spiritual care? And I decided that if there is a God like I think there is, and if God really is part of my life, this is what I'm called to do. And it's either my time, or I get it and I go, or I get it and I die, not go, or I continue to do ministry in the face of this, even though it scares the crap out of me. And it did and it still does. But that was a conscious decision I had to make. I was exhausted a lot.

Powerful testimony of what the pandemic felt like to an HCP working at the bedside in long-term and complex care. I reiterate the point that the pandemic was not a homogenous experience for Canadians. Delilah's days were very different to those of someone working remotely. However, even those remote workers suffered, through amongst other things, isolation and the anxiety of a constant bombardment of media fear.

Delilah now asks me… "if this is going out to the bosses." I reply that anything can be edited out of the interview. She then says… "well, if I'm being honest, edit this out." What Delilah then shares is so raw and vulnerable I believe any human being would only feel sadness, compassion, and love for her situation:

> I skipped work sometimes because it was too overwhelming, I couldn't cope. And I would have, you know, I would have been forced to take days off that I

> didn't have the money for, and I couldn't, I couldn't get out of my bed some days, not often, but some days. And so that's kind of what I lived. And then in the midst of it, having to move my mother in with me and be dealing with patients here who are struggling and her own isolation at home, and that, it was a lot. It was a lot. And it was a very scary time for me.

These few seconds of audio reveal so much of the pain, fear, and suffering that was the lived experience of so many HCPs who worked in long-term and complex care, during the pandemic. I followed up with Delilah later to ask if she wanted those words removed. I had to be careful that I was not applying any pressure or coercing her into a decision she didn't want to make. Fortunately, Delilah felt it was important that the realities of her pandemic experience be shared in the literature. On reflection, she also felt confident knowing she would have the support of senior leadership, working as she does, in a compassionate and caring organization. Yet I relate to her immediate fear of saying something that might "get me into trouble." Having listened to her story, I think the only thing people may think she should get is the Order of Canada.

Delilah then talks about the meaning she experienced during those times. I am reminded of Frankl's words when listening to Delilah. "Man is not destroyed by suffering; he is destroyed by suffering without meaning."[103(p26)] It is when the alcoholic enters recovery and begins to practice the principles of the 12 Steps that their suffering begins to have meaning.

> Also very meaningful, a lot of incredible meaning. And even my mom moving in with us, my mom, who I did not have a good relationship with because she was troubled. And COVID brought some peaceful moments in the midst of all of this, both personally and professionally. So, being able to do sacrament of the sick, even though it was online because the priests couldn't come in, but facilitating that, the RT and I working together, having the family and the priest on facetime and having a baby monitor in the room with the patient and a baby monitor with me and the RT in the room with the patient who is much younger. And we did a risk assessment like, 'Delilah you're not going in the room. I'm not at risk as much as you are. So, I'll go in the room.' Right. And so, there were some beautiful moments and some really scary moments. Yeah. I remember having a panic attack one day and I don't have panic attacks. I'm not like that, I'm not, that's not my build. I usually just power through and find other ways to release anxiety. But remember when we had those hard, heavy plastic masks with the hard heavy… I remember like even now, I'm like (Delilah gasps for air), I remember putting on the N95 and kind of thinking, oh, here we go again. And I put the mask on, and I had to tear everything off. Like I started to panic. Yeah. So, yeah. So, it wasn't fun. I put on a face like everything was good, but no.

> Because the chaplain has to have your shit together, so. And when everybody else is falling apart I got to be the one that's like, okay, let's pull through this. And so, I found that even more pressure in a way, because I have to be the calm in the eye of the storm. That's kind of my role. And I was not feeling calm. But I had to fake it till I made it.

What mistakes were made in the response to the pandemic, I inquire:

> Isolating patients from their families. I would rather have caught COVID. So, this happened to me with my mother. I would rather have caught COVID and died than left her alone and isolated the way we did. And it's why we brought her to live with us, because I could not stand the thought of putting her in long-term care. And we did what we did wrong. I don't know if it's so much what we did wrong but recognising that nobody gives a shit about the elderly, we just don't. Well, when push came to shove, people walked away. Instead of people coming together… I think the medical fraternity, while they did do a lot of good work, they also took too much control and power, and they reveled in it.

I agree with Delilah that Infection Control departments and Public Health had far too much control and power, especially during the early pandemic. This is a point that Dr. Picard the physician participant also raises. Too much power mixed with a near zero risk mentality led to tortuous lives for many of our patients. I also concur with Delilah that the enforced and prolonged isolation of our patients resulted in their significant pain and suffering:

> Well, and it's... like I think there was probably a little bit of ah good our difficult families couldn't come in. Right? And there was a relief in that for us. But that's about us. That wasn't about our patients. That was about protecting our own, like being frustrated with these families and finding them difficult and they're so demanding, and they are all of that. But that's the job, baby. And I think the medical community, not so much in this building because when we made some changes here, particularly after my mum had been isolated and basically died from it. We made a change here right away. I had sent a picture **(Figure 8)** to our medical director of my mom before she was isolated for COVID and after, and she brought it to senior leadership who when they, and they didn't say it was my mother, they said a former patient because she was a former patient here, and they changed the rule right away that day that no more will we isolate patients who have COVID from their loved ones.

Figure 8. Before & After Isolation

I recall my memory of Delilah sharing the before isolation and after isolation picture of her mum with me. It was such a jarring and heartbreaking picture, and a picture really does paint a thousand words. The before and after-effects of solitary confinement are glaringly apparent in the face and eyes of Delilah's mum. This is not the effects of a respiratory virus; this is the consequence of the policies we enacted. It is a testament to both the photograph's power, and the humility of the hospital's senior leadership, that on seeing the picture the hospital's isolation policy was reviewed and revised.

I share with Delilah that my mum was palliative with heart failure in the midst of the pandemic:

> My sister couldn't see her mum for the last month of her life. I felt terrible travelling to England to spend a week with her and knowing that she was dying… If you were travelling at the time people would be shaming you. In fact, my employer actually told me that they were getting a legal opinion as to whether it was ok for me to travel to my mum's funeral.

It seems almost ridiculous now that somebody would require a lawyer's opinion to grieve with their family and bury their mum. Yet, this was the dark place that the collective fear and shame had driven us to. On reflection it was almost a kind of mass

hysteria. I must not have completely grieved and accepted as I still feel some anger when writing these words. Delilah then shares:

> See, that's the kind of stuff that it's funny because at the time I didn't realise what the medical community was doing was wrong, but my husband did. He said, ‘how can you be okay with the fact that we just gave up our freedoms and allowed the medical community to take so much control?’ At the time I was overwhelmed here, so I didn't see it. But he was absolutely right, and I even had to shut him down and say, ‘I can't hear this shit when I come home.’ I'm so overwhelmed and stressed and then I've got to focus on our 16-year-old who's crashing and you're loving this because you're an introvert, but the rest of us are really struggling. And I said, ‘I can't hear this.’ And then he was hurt because he's like, ‘well, but what I said was right.’ And now I know he was right, but I could not have accepted it then because there was too much going on. Like I was working in healthcare. Had I not been working in healthcare I might have had a different perspective. There was a lot of power that came with, I'm the one who's going to do everything for you and tell you how to do it; and I'm the one who's going to sit with your loved one while they die; and I'm the one. There's a little bit of power tripping that goes with that, you know? But by and large, in this building, it was moral distress about watching people die alone and watching loved ones crying because they want to come in and navigating that with compassion and care and still saying, ‘I can't let you come in.’ Mind you, I screwed it around that for a patient who was dying and their nine-year-old child, I thought if we get a COVID outbreak because a mother gets to hug her child goodbye, I don't give a shit. I really don't. We went out onto the patio outside. I PPE'd the hell out of that kid and out of his mother. I said, ‘I'm going to turn my back now. So, if he runs into your arms and hugs you, I'm not going to see it.’ And that is how I managed some of the moral injury and pain that was going on.

Delilah’s connection with her higher power gave her the moral courage and the knowledge, that despite all the fear mongering and shaming, it was right that this young child got his one and only opportunity to hug his mum and say his last goodbye. Many HCPs, in many similar situations, did not allow the child to hug their mum goodbye; the child lives with that emotional trauma and the HCP lives with that moral injury.

I am interested in how Delilah viewed the hospital’s vaccine roll-out, particularly as I was personally involved in assisting with the hospital’s vaccine program and having suffered some moral distress at receiving the vaccine four months before our patients. Delilah explains:

> I was pissed. First of all, the people who weren't even at the bedside were getting themselves vaccinated first because they were complaining. And I'm thinking of some Allied Health people, like I'll name it. And I was pissed that we

> weren't vaccinating our patients first. But it maybe it's like the oxygen mask. You have to take care of yourself first to take care of others, so I can make sense of it that way. What I couldn't make sense of is the disparity in how some staff who complained and pushed harder got their vaccine sooner. I was living with my 82-year-old mother, working in healthcare. You know, if anybody was like a frontrunner for a vaccine, it would have been me, 50 whatever at the time, diabetes. I had all the markers for we should do her first. But I didn't push and scream and complain like other people did. And I feel that morally kind of I went that's gross. What you guys are doing is gross. And there was a lot of virtue signalling, too, during COVID that I didn't like. I'm a healthcare hero. No, you're not. You're a nurse who went into nursing not to be a hero, but to nurse. So shut up and nurse. Like the same with me. Like, shut up and chaplain, don't say, 'Oh, look at me working.' You know? No. So there was a lot of moral er...I'm not sure injury is the right word, but discomfort about some of that.

Hindsight is 20-20 and I believe most HCPs, knowing what we now know, would have advocated for our in-patients, many of whom were elderly with multiple comorbidities, to have received the vaccine first. In the hospital's defense I know that their hands were tied by Provincial mandates and policies, and as soon as was logistically possible they rolled out the vaccine to the patients. Does Delilah believe we are ready if there is another similar pandemic:

> Oh, hell, no. We've forgotten everything. No, we're not. Because we haven't learned our lessons. We're still not prioritizing senior healthcare and mental healthcare. We're still you know, if this happened again, they would still say isolate everybody. We know that doesn't work. You know, there are family members who would have accepted getting COVID. And like when mom was in the hospital, I said to that manager, 'I will take time off work so that I'm not going between two hospitals and putting anybody else at risk.' And that was before I was getting paid leave. And in fact, because I didn't have full-time benefits, I said 'I will take unpaid leave and come and care for my mother, she wants me anyway. Let me do it. I know how to don and doff PPE.' This nurse manager, she was like, 'well, you know, how do we know you're just going to leave the hospital?' And I said, 'do you have a transporter for your other nurses? Like, how do they leave the hospital? They go from the patient unit out the front door and to their cars. I'm going to take the same egress.' Like, what's the problem here? There was this power tripping and this inability to learn that from the first round, the first wave and the second wave... and because mom was the fourth wave, right from the first, second and third wave that you can't isolate people like this. They didn't get it. They didn't care. They were power tripping. Seniors don't matter… it's not about putting people first. It's about putting agendas first. So, I don't think we will learn… I know it sounds depressing, but my wisdom tells me, because it was the same during SARS (2003). I worked in hospitals in Toronto during SARS and it was the same thing. As soon as the... SARS had two waves, the first wave was about to end I was

> working in the neuro ICU at St Mike's, and they dropped masks the day before and two days later there was an outbreak in the neuro ICU and then... up we went again. So, it's people, we just don't learn. We don't, we're still having wars. People are still starving. People are we're not learning. We're just not a society of learners I don't think. I think whatever exists in the universe looks at us and goes, man you guys are screwed. I just think there are pockets of people who treat each other well, which is great. But I think overall we don't learn our lessons. I don't think we do. I think you and I might, and others in this building, and I know our senior leadership team did as soon as they saw that photo. But I don't know if for the next pandemic we have a clear and coherent plan. I think everybody thinks this is it, which is ridiculous because it's not. So, I'm a real upbeat interviewee, aren't I? Whoa, we're going to hell in a handbasket!

In the situations described by Delilah I am unsure if the pleasure of using power to control other people, power tripping as Delilah calls it, was the primary intention for the majority of management personnel. Some people may certainly have felt vicarious pleasure, however from my vantage point in the pandemic it appeared the majority drivers of behaviour were (as is often the case with human beings) fear and ignorance. A principle I adhere to is to never assume maleficence where ignorance will suffice.[72] Unfortunately, I do agree with Delilah that we are not prepared for another pandemic. Like the alcoholic in denial before he confronts his illness through practicing the 12 Steps, what we do not acknowledge, we cannot change. Until we have an open, truthful, and reconciliatory Public Inquiry of our pandemic response, and the policies we implemented, we will not be prepared. Outside the hospital these policies resulted in significant adverse effects on economies, resulting in the single biggest wealth transfer in history, of five trillion dollars, from the working and middle classes, to the elite.[349] Furthermore, it resulted in, and continues to affect, the mental health and well-being of billions of people, which were negatively impacted to a significant degree by the lockdowns.[350]

4.11.1.3. Healing from & Dealing with Moral Distress

How did Delilah deal with and heal from those experiences of moral distress and moral injury:

> I drank a lot. No, I didn't. I'd like to say I prayed and found God in it. But no, I really struggled. I went on antidepressants. I tried to find meaning with friends in the community, and I did. I made real efforts with my family. We did a Zoom thing for Mother's Day the first year. I made baskets for everybody, all the

> moms in our family with sparkling lemonade and flowers and little handmade cakes and some other stuff and sent them out. And then I did a family video for Mother's Day of all the moms in our family through the years and tried to connect that way, and that was nice. And it did bring our family a little closer. And so that was a positive.
>
> At the hospital it was just a matter of trying to find light moments and dark humour and supporting staff, but also letting staff support me a little, too. And like ignore me if I tear up, but when mom first came here from acute care, the first time before she moved in with us, and she went on a unit here, and I said, 'hi mom' from the doorway. And a nurse goes, 'you go in there and hug your mother.' And I hadn't hugged her in three months. I burst into tears. Yeah. So, moments like that were what kind of buoyed me and got me through. Hanging out with people on Zoom. But the reality is it was hard and trying to sugarcoat that and say I didn't have any moral distress, and it wasn't, would be lies. You know, people who say they were just fine, they're lying because it was hard. We all felt kind of like, 'shit, is this the world now?' Like, I remember a colleague saying to me, 'can I never hug you ever again?' Like that was the fear. Right. She's a big, touchy-feely, huggy type. So am I. And because I said to her the first week, she was going to hug me, I'm like, 'you can't hug me, we can't do that right now.' And that was devastating. You know, now I was at home with people I could hug. Right. But for people who need that physical connection that was pulled away, especially our seniors. So, I found little ways, little pockets, little islands. I think the thing that hit me hardest was losing my faith community. Was when they had to close the doors to church that first Easter because Good Friday and the Easter vigil are very important to me and Easter Sunday more than Christmas. I find those to be the most meaningful ones for me. I drove to the church and sat outside and cried on Good Friday. I just because I was so like, oh my God, I'm not allowed to go to church. Like, what is happening?

Delilah's anger at the draconian curtailment of civil liberties and the abolishment of religious community is shared by many. US Supreme Court Justice Gorsuch wrote that… "Fear and the desire for safety are powerful forces. They can lead to a clamor for action — almost any action — as long as someone does something to address a perceived threat."[351(p6)] How very true. In this rare personal commentary, which shares many similarities to what happened in Canada, he writes:

> We may have experienced the greatest intrusions on civil liberties in the peacetime history of this country… Governors, and local leaders, imposed lockdown orders forcing people to remain in their homes. They shuttered businesses and schools, public and private. They closed churches even as they allowed casinos and other favored businesses to carry on. They threatened violators not just with civil penalties but with criminal sanctions too. They surveilled church parking lots, recorded license plates, and issued notices

> warning that attendance at even outdoor services satisfying all state social-distancing and hygiene requirements could amount to criminal conduct.[351(p4-5)]

Strange times indeed. My own spiritual recovery community was ripped away overnight as church basements were closed to 12 Step meetings. Yet bizarrely, if I had wanted to, I could have gone to the Beer Store and got drunk. I share with Delilah that, for me, the pandemic was horrible. She says, “I remember seeing you and worrying about you and you not looking like you look now.” I reply that “it was horrible, having my mum dying in England at the same time.” Delilah shares the insight of a colleague into our unresolved collective pandemic trauma when she states that… “none of us are talking about it… A social worker, who used to work here, said ‘people are stressed and freaking out and nobody's recognizing why we're like that and we're not dealing with it. Nobody is talking about the big trauma.’ One of the recommendations from this research, which will be expanded upon in Chapter Five, will be pandemic specific and time limited facilitated group interventions. These have been shown to be an effective tool to improve the mental health of HCPs and reduce their symptoms of distress.[352]

I share with Delilah that… “people say things now and I get a visceral reaction like, oh, my God, I forgot all about that. And it will trigger something which happened two years ago. And the feelings will come back up.” Delilah replies:

> Well, that hug the nurse let me have with my mom. You know, that's rough. And having to ask a chaplain at another hospital, for one of our patients whose husband died, we're pretty sure of COVID at that hospital, to go and just stand at the glass of the ICU room so she could look at her dead husband she'd been married to for 63 years. The chaplain didn't want to do it. It's just like, get your fucking ass up to that ICU because I have a woman in agony right now because her husband died and she can't be with him. I said, ‘it’s the very least we can do. Don double PPE. I don't care. I'm not asking you to go in the room with him, which, by the way, wouldn't matter because you're not breathing particles anymore. But stand at the window and just let us see that. And I will do prayers while you do that.’ But it was the reticence that the chaplain didn't want to do that. Talk about there's a moral, a moral moment for me. I was like, oh my God, you're not going to say no to me. And my boss was like, ‘well, you can't force her.’ I said, ‘I sure as hell should be allowed to. We are supposed to be the moral guides in the midst of all this stuff. I'm scared. Do you think I want to be going in a room with a woman who when she last saw her husband, he probably had COVID. No. But here I am. And I'm nobody special.’ And so, we haven't... See, I'd forgotten about that. And this conversation is... I’m going to

need therapy after this, buddy. But yeah, we have not dealt with the trauma and the pain that we suffered.

I mean, I got to do a really healing thing. Two years ago, when the vaccinations first started, and we're kind of sort of thinking, oh, we might have a normal life again, I was asked to go and do some workshops with the Sisters of Charity. Because they had been locked in, they call their rooms cells... I'm not being dramatic. They've been locked in their cells for three months, basically, and for the first time in their lives, they were not in the community working the front lines. So, for them, introverted nuns who like to pray and like to, you know, it was fine. For the nuns who were extroverted and working in the community and had purpose and were even if it was just volunteering at the hospitals, they were relegated and they felt it. They lived it hard. They struggled. So, I was asked to do some sessions with them. So, I did a series of six weeks of sessions with groups. I think I had said no more than six sisters at a time, and it was an all-day session, and it started with first letting them, and I had to do it in French too. It started with letting them talk about what they lived, right? And there was a lot of anger and hurt. And then we moved from that into how do we go forward in hope and in peace. And then we did a live butterfly release at the end, and that's why I have this butterfly charm now. And it was very healing; but I don't think the world has done that. Like the Sisters of Charity knew, the sisters needed something like that, but I don't know if anybody else in the world has been doing that, do you?

Most of the HCPs I know, and many in this study, have not been provided an opportunity to talk about, process, and heal from, their experiences of working on the frontlines during the pandemic. Although I cannot state with certainty, and it is unwise to extrapolate from a small qualitative study, it is likely that many HCPs carry unresolved moral injury and emotional trauma from those times. Delilah is obviously a deeply spiritual and religious person and so I ask how that helped her during the pandemic:

I'm not sure my religion helped me personally. It helped me personally in the sense of doing for others despite what I was living, because that's what we're called to do, right? I had a hard time praying during the pandemic. I did, but it didn't do a lot to comfort me. The sessions I did with the sisters really helped me because I thought, wow, if nuns lived it hard, like, okay, like it's okay that I lived it hard because these ladies are so connected to God, then if they were having trouble, if they were angry and struggling, then, you know, who am I to think I'm special? And so, there were times where I couldn't connect. And I think part of that was protecting myself too because my church had shut down. That's a church I've been going to on and off since I was seven years old. I'm an elder in that church now. I've been going there so long; I know the history. For me, that was, and I went with my daughter, like we were part of that faith community. She would read with me. We would, I read the first reading, she'd

> read the second. Sometimes I preach there. We were very deeply involved in the liturgies there. And so, to have that shut was brutal.
>
> The first time I got to go back in that church was to do a funeral for a patient from here. So, I did a memorial in the church. They didn't have a priest who was available or wanted to do it. And our parish priest was afraid of COVID and wasn't doing a lot. And so, the church administrator and I decided that I would do the funeral for the family if they were okay with it, and it was a family from a unit here. It was the first time I was allowed back in my church and that was depressing. Everybody, like in the worst time of their life, and they're all like six feet apart. That's not what this shit's about.

As Delilah states, it was brutal. I share how at my mum's funeral we were told to sit, and the chairs were spaced, six feet apart. We started off six feet apart and within 5 minutes everybody was sat next to each other, hugging and crying. Hugging and grieving and also feeling guilty and afraid at the same time; frightened I will give someone COVID and kill them. Delilah shares her own guilt from those days:

> Yeah. There is unresolved grief up the wazhoo post the pandemic. Like I lucked out in a way. I mean, the last three weeks of my mother's life were horrific. And I felt a little scintilla of what you lived. But I'm lucky in that I had a physician here and a bunch of nurses from here and another hospital who said, 'take her home, we'll help you.' And so, I took her home and we did. We gave her a good death. But, you know, if that had been two years earlier, I wouldn't have been able to do that and I would still be messed up, you know. And so, I feel for people who had to live that and aren't sure. Like I feel still guilt that I left mom there for two weeks. Isolated, right? I don't know how people are getting through the guilt of even though it's not their fault not being able to be there. You know, it's not your fault that the governments did this, and rightfully or wrongfully, who knows? But how do we process our loved one dying alone like that? You know, how do we, how do I process my mom feeling like I'd abandoned her for two weeks? And I remember crying when she got home. It was the second night, and she was in a lot of pain because the dickhead Doogie Howser, would not give her the pain meds that she'd been on in the hospital. He dropped her back to what she was on before the surgery. So of course it wasn't good enough. And of course we couldn't get the system to react quickly. And of course, of course, of course. And we gave her as much as we could without doing damage. Right. But she was still in pain. And I remember at about 3 a.m., I broke down sitting at her bedside going, 'Mom, I'm so, so, so sorry that I couldn't get you out sooner. I tried; I tried. I tried.'
>
> It's a tough one, in terms of how did people get through it. And so, my faith. I look at things now and think, you know, I was fortunate, but I don't think God helped me, but not you. My cousin was in the same boat and my aunt was dying in Toronto and my cousin was not allowed in to see her, not even at the

> door, nothing. And I gave her, I don't know if you remember, I had those gold buttons that we could record and then people could push so the patient could hear our voice. And so that like when we weren't readily available. So, I did one of those for my cousin, and my cousin brought it to my aunt, and it was my cousin and her sister and the grandkids just one by one saying they loved her. And the nurse told my cousin that my aunt, when she heard my cousin's voice, kind of looked up as if to look around for her. So, she recognized that was her daughter and that helped my cousin. She said it felt like I was kind of there even if I wasn't.

I recall when my mum had been discharged from the hospital, and before she went to the hospice, helping her on and off the commode and she looked up to heaven and she just said, “thank you so much God for sending Paul home.” Delilah says… “I just couldn't get my head around that God would provide for one family but not another. I couldn't even like credit God with stuff like that. I had to figure out that God is giving me and others in this building strength to get through this.” Finally, what advice would Delilah give to another HCP when dealing with moral distress:

> Talk. Talk it out. Find people and talk, talk, talk, talk, talk. Until you start to talk about it and you're like, oh, I'm over that. Like, talk it through. Talk it through. Talk it through. In talking, you might come up with solutions on how to deal with it. In talking about it, you might realize, hmm, I shouldn't be working anymore. In talking about it you might just get enough of it out that you can keep going. Yeah. Reach out. Get help. Talk to everybody. Talk, talk, talk, talk, talk. That's what saved me.
>
> When that horrible thing was happening to mom in acute care and I was venting on Facebook and really angry, and people were reaching out to me because of that. And I needed that, you know, And I couldn't call everybody and tell them sorry. And my boss, his brother was on my Facebook, and he told her and she said, ‘you need to be careful what you're saying.’ And I said, ‘no, I don't.’ I said, ‘acute care are doing a horrible thing. I'll call it out.’ I stopped short though… a CBC producer approached me to talk to me about moral injury based on this. And I talked to comms here and I said, ‘you need to tell me I can't do it because right now I'm so angry, I'm going to do it.’ And she said, ‘I can't tell you not to, but you know, you shouldn't because it's just not a good time for that. We can't pitch hospital against hospital.’ And she was absolutely right. But I was not in the headspace to make that decision for myself. So, it was great. Like our comms director was actually quite good. Said ‘I'm really sorry you're living in this. I think it's terrible.’ And then when the time came, I wrote a seven-page letter with a colleague’s help to the acute care hospital about what they'd done wrong.

> So, talk, share, you know, brainstorm, you know, careful who you trust, but find your group and trust and talk. And if somebody is not understanding, keep going. EAP was useless during COVID to me. They never returned my call. They were so busy. So, I had to like, okay, I went down that road, that didn't work, I'm going to go down another road. I did this emergency… they had these emergency lines for talking to counselors. If you're struggling, I got somebody who was like, 'how does that make you feel?' I'm like, okay, no. And so, you know, I dropped her, and I kept going until I found someone. So that's what I would say. Just keep trying, keep talking, keep reaching out. Don't stop.

Keep talking and keep reaching out. Sadly, very few HCPs are talking. We were not provided the space, nor the time, to talk, process, and grieve. However, when we bury our feelings, we bury them alive. It is never too late to talk. Never too late to deal with the unresolved moral injury, moral distress, and emotional trauma. It is never too late to heal.

This chapter was far more substantial than the results section of a typical quantitative report due to the extensive verbatim transcript extracts and interwoven detailed analytical interpretations and commentary.[168] There was no clear demarcation between results and discussion, with the case results and discussion merged into this chapter, and written in the first person perspective.[168]

Four overarching Group Experiential Themes (GETs) were identified **(Table 2)**. These GETs were emotions, dealing and healing with moral distress, meaning and resilience (faith), and associations of moral distress. Personal Experiential Themes (sub-themes), many of which were shared and some unique, of each participant were explored and interpreted, using extensive verbatim quotations. These results have comprehensively incorporated the perspective of both the researcher and the participants. IPA emphasizes the importance of an idiographic emphasis, and this thesis is distinctive in its focus, powerfully reflecting some of the experiences of ten HCPs working on a long-term ventilation unit.

In Chapter Five I will present a summary of these results, provide recommendations at the organizational and personal level for dealing with, and healing from, moral distress, and offer some future research opportunities.

Chapter 5. General Discussion

5.1. Summary Discussion

The purpose of this research was to explore the phenomenon of moral distress, through an interdisciplinary research lens, looking at the whole multidisciplinary team caring for patients requiring long-term ventilatory support. These HCPs were drawn from the disciplines of nursing, clinical management, medicine, pharmacy, respiratory therapy, physiotherapy, spiritual care, and social work. This study is unique in exploring moral distress in this population and environment.

Chapter One presented the background to this study of moral distress in HCPs caring for patients requiring long-term ventilation, predominantly viewed through the interdisciplinary lenses of 12 Step spirituality and virtue ethics. There are many shared symptoms, sequelae, and concepts, such as shame, powerlessness, acceptance, forgiveness, helplessness, and hopelessness found in moral distress and 12 Step spirituality. Chapter One provided a general explanation to the reader of 12 Step spirituality and virtue ethics as they may pertain to moral distress and how we might deal with and heal from moral distress.

Chapter Two undertook an interdisciplinary review of the literature on moral distress and the closely related phenomenon of moral injury. The works of Georgina Morley and Carolina Caram, foremost researchers in the study of moral distress, were reviewed. The intent was to broaden our understanding and challenge preconceived opinions, regarding the subject matter relevant to a study in moral distress. Furthermore, Chapter Two explored the literature regarding the ontological and epistemological conceptualization of moral distress, both generally and through a virtue ethics perspective, and discussed the closely related phenomenon of moral injury.

Chapter Three outlined and validated the methodology, research design, population, sample, data collection methods, and data analysis procedures of the study. As its primary focus this study utilized an interpretative phenomenological analysis in order to facilitate a fulsome and comprehensive understanding and interpretation of the experience of multidisciplinary HCPs caring for patients on a long-term ventilation unit.

The participants were selected and invited to participate in the study based on a selection criterion that created a homogenous sample of HCPs, from a variety of different professions, working on a long-term ventilation unit. In-depth interviews and the MMD-HP validated moral distress questionnaire were used as data collection sources to capture the experiences of the participants in relation to moral distress on a long-term ventilation unit.

Chapter Four presented the findings, discussion, analysis, and interpretation viewed through the lenses of 12 Step spirituality and its virtues and practices. Four overarching themes, Group Experiential Themes (GETs), were identified, as presented in **Table 2**. These GETs were Emotions, Dealing and Healing with Moral Distress, Meaning and Resilience (Faith), and Associations of Moral Distress. Analysis of each different professional's experience of moral distress working on a long-term ventilation unit was provided. Chapter Four was substantial due to the extensive verbatim transcript extracts and interwoven detailed analytical interpretations and commentary, with the case results and discussion merged into this one chapter and written in the first person perspective. These findings comprehensively incorporated the perspective of both the researcher and the participants. This thesis is distinctive in its focus, reflecting some of the experiences of ten HCPs working on a long-term ventilation unit.

In Chapter Five I will now present a summary of these findings, provide recommendations at the organizational and personal level for dealing with and healing from moral distress, and offer some future research opportunities. This summary discussion will follow the three headings used in Chapter Four, namely Meaning & Faith (Resilience), Emotions and Associations, and Healing from and Dealing with Moral Distress. Once again to improve the flow and readability of this section, the GETs of Emotions and Associations of Moral Distress are grouped and summarized together. These four GETs are not absolute and isolated, and there will be some spillover between the four GETs.

5.1.1. Meaning & Faith (Resilience)

Though all the HCPs articulated their understanding of moral distress differently, their concept of moral distress shared similar themes. Fundamentally the participants see

moral distress occurring when the HCP is prevented or unable to do what they think is right, which then causes suffering for the patient and/or the HCP. As Nela states simply and yet powerfully, moral distress is… “when you know you are doing something that's unnecessary and you don't have the power to change it.” Jean-Luc, the physician, described a triad that he saw as fundamental to the development of moral distress. This triad is… “what the patient wants, what the family wants, and what the medical system is able to offer. When those three are aligned, you have no issue. Medical system is able to offer what the patient wants and what the family wants, we're all good. When one of those is out of alignment there is a conflict.” Jean-Luc also shares a healthy acceptance of his powerlessness in some of these situations when he says… “and there's a difference between I'm unable to do it because it's not doable. That for me doesn't cause moral distress. If I'm unable to do it and it is doable, that's a problem.”

All the HCPs shared on the sense of meaning that their work provided them. The nurses described this as… “caring for people and making them comfortable... knowing at the end of the day that you helped them,” and the… “desire to help people. To make a difference.” Faith described how she changed careers to become a nurse and how… “At the end of the day, when I got home, I didn't feel I had made any difference in anybody's life. So, I went back to school and took nursing… that's probably the best thing I have ever done.”

Sarah, the social worker, described how she had personally been helped by social workers and how this guided her career choice. Jean-Luc, the physician, came from an extended family of physicians and other HCPs and his career choice was almost pre-ordained. Malcolm, the pharmacist, explained how… “I like to help people, and I find learning about drugs interesting. So, I kind of married both interests together.” Nadia, the respiratory therapist, shared how her role allows her to foster an increased sense of meaning when caring for patients and to develop a deeper sense of connection. Eleanor, the assistant manager, explains that even though she has moved away from bedside nursing she still has the… “same relationship with the team and with the patients. So, I get to interact with them still.” It was important for Eleanor that she still has contact with the patients and how as a bedside nurse on the unit she would… “spend a lot of time caring for the patient, a lot of time to build trust, getting close to

them, getting to know them before, what their life was like before their accident or before their illness."

Delilah, the chaplain, explains how she finds meaning in her work by helping patients and their families… "understand the meaning and helping them do the journey towards finding some sort of understanding or meaning." Joe the physiotherapist enjoys… "working with people who are in great need of some services that I could offer… I found that to be a passion. Taking someone who has a lot of problems and helping them a little bit with some of them, I found really fulfilling." Interestingly Joe also found meaning in moral distress itself… "Moral distress is something that encompasses this occupation and this setting, and it's one of the reasons I really take part in it.… It's interesting, it's fulfilling, it's meaningful, it's challenging, and it helps build character and build life experience."

Practicing the principles of the 12 Steps on a daily basis eventually gives meaning to the alcoholic's suffering, while at the same time allowing him to gradually suffer less. Practicing those principles and virtues inherent in 12 Step spirituality, such as acceptance (Step One), self-honesty (Step Four), and courage (Step Five), may also bring meaning to the HCP's moral suffering. Many of the participants shared that their spiritual and/or religious beliefs provided strength and an ability to accept life on life's terms.

It was interesting to note how the HCPs articulated and conceptualized their spirituality. Veronica, for example, shares that for her spirituality means… "there's something bigger than just us… it's having a connection to something other than yourself and the people around, because I would consider that we're all one; we're all connected somehow." She further explains that it… "helps me a lot. It's something that I turn to in my more difficult times now. And it's like a gentle reminder to myself and my inner self that things are going to be okay and that I can do the things and keep moving forward and have the confidence to do the things I need to do. Just overall it brings me a sense of comfort." Another nurse, Faith, shared the joy she receives caring for her patients and how… "every day when I take care of a patient I serve God." Sarah, the social worker, sees spirituality as… "believing in a higher power. Being kind. Being nurturing. Having a voice

when needed to speak up for those that can't." Importantly her sense of spirituality fosters a healthy state of acceptance… "Then also just accepting what you have as part of life… maybe that's how I found solace through the pandemic. That's just what we had in that moment and there was no changing it, and we had to work with what we had."

One of the unique insights from this research is the contrast between helplessness and powerlessness. Due to the lens of 12 Step spirituality this research has uniquely highlighted a significant epistemological and ontological difference between powerlessness and helplessness in moral distress on a long-term ventilation unit. Acceptance of our powerlessness to the majority of what we face in life, is paradoxically a positive empowering state of being; passive helplessness is not. Just as shame is ultimately a lie, so is helplessness.[8] In an ethically supportive organization, help is always available.

Eleanor describes this sense of helplessness well… "When I was still working at the bedside, a lot of us would vent to each other and speak about our frustrations and how we felt the family didn't understand and that we didn't feel supported by the physicians or by management to have these difficult conversations, or we weren't… kept in the loop." Here she is feeling unheard and unsupported. The issue she saw was that… "no one was communicating what was actually being done with us… The nurses would also feel sadness. Frustration. Helplessness." Note how different this is from a healthy state of powerlessness. What the nurses needed was to know that their voices had been heard, acknowledged, and valued. That they are truly part of a team and that their knowledge and experience is valuable. They needed to know the rationale for the orders they would be implementing. This speaks to the importance of having nurses front and center of multidisciplinary team rounds.

In moral distress literature the terms helpless and powerless are often used interchangeably. However, due to the application of a 12 Step lens to the phenomena, this research has shown that there is a difference in these terms when HCPs speak of morally and emotionally distressing circumstances. Sometimes powerlessness and helplessness may be used to describe the same thing, yet in some cases the HCP is attempting to describe two distinct phenomena. Helplessness is the feeling when one is

frustrated, impeded, or you believe it is impossible to make something better. You feel like a child watching two parents fight – scared, sad, and helpless. Malcolm, the pharmacist, described it as feeling handcuffed. Those feelings of helplessness, if internalized and given a justification story, stunt us and leave us stuck. In 12 Step spirituality powerlessness is a primary and fundamental concept. Positive acceptance of our powerlessness is the necessary precursor to healing and growth. This is not merely academic semantics, as how we conceptualize these events in healthcare will have a direct impact on our resilience and elasticity. Thus, changing our understanding and perception of these particular phrases and how they are articulated can shift our experience, coping mechanisms, and morality. Furthermore, using the word… "powerless to represent the situation and characteristics of the event, and the word helpless to represent our internal and external reaction to an event,"[340] provides the opportunity for the development of resilience.

Of paramount importance is having the wisdom to know when to accept what cannot be changed and when to courageously change what can. In 12 Step spirituality the foundational prayer is the Serenity Prayer – "God, grant me the serenity to accept the things I cannot change, courage to change the things I can, and the wisdom to know the difference."[224] In practicing the 12 Steps of AA, particularly Steps Ten (self-inquiry), Eleven (prayer and meditation), and Twelve (selfless service), this wisdom comes slowly to the recovering alcoholic.[7] From a secular perspective mindfulness and reflection are tools that HCPs can use to help them begin to see the difference between a positive state of acceptance of a particular healthcare reality, and a negative, passive, and rigid state of helplessness.[17] For Veronica her mindfulness practice helped her to understand that… "I can only do the best that I can do when I step into my workplace. I don't have control. I mean, I actually have control over nothing." Ethics consultation services can facilitate these moral distress consultations and provide the guidance and education staff may require.[353]

5.1.2. Emotions & Associations of Moral Distress

The feelings of anger, fear, helplessness, sadness, guilt, powerlessness, anxiety, frustration, hopelessness, and shame were not surprising findings. All the participants

experienced moral distress. However, the intensity, frequency, and duration differed between professions. The physician, Jean-Luc, experienced very little moral distress outside the pandemic. As a physician, who typically enjoys significant personal autonomy and is least affected by institutional constraints, he was particularly at risk when medical power and decision making were given over to Infection Control during the early pandemic. This resulted in moral distress, anger, and frustration. Why? Because he knew the right thing to do but institutional constraints made it nearly impossible for him to pursue the right course of action.[24(p6)]

Many of the HCPs reported guilt with some displaying significant ongoing shame. As previously discussed in Chapter One, guilt and shame are distinct phenomena requiring different treatment modalities. Guilt is "I did something bad," and shame is "I am bad." In 12 Step spirituality all the Steps, but particularly Steps Eight and Nine (forgiveness and amends), and the fellowship of AA, provide the light and healing for the alcoholic to finally realize that shame is a lie. For our HCPs who report a significant moral injury and shame it is recommended we consider providing Acceptance and Forgiveness Therapy (AFT). AFT is a psychospiritual group intervention that guides a person with moral injury… "experientially from a trauma-focused (damaged, broken, guilty, unforgivable, hopeless, unacceptable) to restorative (worthy, connected, hopeful, forgiven, responsible) view of self."[89(p57)]

One of the nurse participants reported leaving the long-term ventilation unit, in large part due to the moral distress she suffered. Vitally, the primary causal factor to her moral distress was repetitive exposure to the rude, aggressive, demeaning, and uncivil words and behaviour of a small minority of patients and/or families. In her own words she… "was coming in to work to be somebody's emotional punching bag." One cannot overemphasize the profound detrimental effect patients with behavioural issues have on all who work in a hospital or are cared for in a hospital. This research shows how due to the excessive amount of time behavioural patients frequently demand of the HCPs caring for them, staff are unable to provide the required time and support to other patients. It is these other patients who then suffer as a result. Furthermore, it was revealed that because staff are often frightened of patients with behavioural issues, they sometimes limit the frequency and duration of their visits, which in turn may negatively

affect the care of these patients. Not unexpectedly the nurses at the bedside experienced repeated and at times intense moral distress. This was in part due to their limited autonomy, need to follow physician orders for which the rationale was unclear to them, and experiential exposure to the consequences of those ordered actions.

The voice of pharmacy is little heard in the moral distress literature, and so it was enlightening to hear a pharmacist's experience of moral distress, its causes and how he dealt with the situations that arose, often in the interprofessional relationship with the treating physician. Malcolm's insightful articulation that for pharmacists… "a lot of moral distress in pharmacy is the process and not necessarily the people," is well received. Improving the process of physician order entry for medications will be recommended. The testimony of the chaplain was powerful and moving. In her decision not to join a regulatory College she experientially highlights the point made in Chapter Two, that virtue ethics addresses important questions that professional codes, or hospital policies, may neglect. She explicitly revealed how these codes may limit words or actions by considering them to be permissible, obligatory, appropriate, or inappropriate, and how an action could have different possibilities, if the chaplain invoked virtues which leads them to act morally in their practice. For Sarah, the social worker, the More Beds, Better Care Act (2022) was a significant source of moral distress. She shared her struggle to work within an Act she felt was immoral and caused unnecessary suffering to her patients. If the Charter Challenge proves successful and the Act is deemed illegal, it would be interesting to go back and see if this would cause retrospective moral distress for Sarah.

It was the pain and suffering I personally both witnessed and experienced during the pandemic which ultimately led to this research. The HCPs' stories laid bare the suffering that they experienced, both personally and professionally during the pandemic. The fear, shame, and shunning were woven throughout their sharing. Many of the HCPs reported feeling guilt at the increased freedoms that they enjoyed when compared to their patients. The social worker was another participant who had left the unit due to the moral distress she experienced, particularly in relation to the pandemic and the issues with the new physician.

Nurse Nela spoke of returning from a vacation at the beginning of the pandemic… “then I came to the floor, and everybody knew that I had just come back so nobody wanted to use the computer I was using. Nobody wanted to sit on the chair where I sat. If I touched anything they would come and disinfect after me… I just felt unwanted, not welcome, and it was a horrible experience.” Faith described how the… “Fear, the anxiety, the stress that we were in was unbelievable.” To protect her family Faith… “slept in the basement for almost three months. I saw my kids on FaceTime down in the basement, and my husband. When I was sick, they just threw food by the door and left. Just like a dog.”

The profound suffering imposed upon their patients by isolation policies generated significant emotional and moral distress for many HCPs, with comparisons to being in prison articulated. The photograph of Delilah’s mum after 14 days of isolation is still difficult to see and a blanket policy of prolonged and repetitive isolation must never be allowed to happen again in similar circumstances.

The physician who is no longer on the unit caused significant moral distress not only for the nurses but also for the other health professions on the unit, such as social work, physiotherapy and respiratory therapy. Many spoke of the false hope given by the physician to a patient and her family. Sarah, the social worker, shared how he… “would make recommendations that would go against what the care team had said would be most appropriate for the patient and would constantly request or write orders for things that go beyond the scope of what as a team we could provide.” She shared how, because of the delay to the natural grieving process, false hope had also caused the patient and their family significant harm. Nadia the respiratory therapist shared… “It's frustrating because you can only do what you can do within your professional capacity and you don't want to overstep what the physician is saying or doing, but we do keep reinforcing the reality. But it's almost like talking to a wall.” Eleanor, the assistant manager, shared how this had affected her and what she had felt when she was a bedside nurse… “Frustration. Helplessness. Sort of being silenced in a way. Not that it's my job to give a diagnosis or a prognosis but knowing something isn't accurate and not being able to say anything, sort of having to go along with it because it doesn't, the team

doesn't, seem united if the doctor says one thing and the nurses say that's not going to happen. So, it's just a feeling of frustration and helplessness."

Once again we are given a glimpse here into the subtle experiential distinction between helplessness and powerlessness. As a beside nurse Eleanor viewed herself as… "not being able to say anything." This false belief kept Eleanor frustrated. The truth, as evidenced by the fact that when the multidisciplinary team brought their concerns to senior leadership the situation was eventually rectified, is that in an ethical and supportive organization an HCP is never helpless and without a voice. It is the organization's responsibility to ensure that its staff are aware of this and most importantly feel and believe it to be the case.

Documentation burden was a significant stressor particularly for the nurses and physician. Medicine appears to be ahead of the curve when it comes to the use of AI and/or scribes and recommendations for reducing nursing documentation burden are provided later in this chapter. Surprisingly Joe, the physiotherapist, found his documentation routine simple and reflective. This is likely due to a reduced documentation burden and allocated non-patient care time for completion.

5.1.3. Healing from & Dealing with Moral Distress

Many participants shared the tools and practices they use to help them work effectively as HCPs and function in their daily lives - mindfulness, meditation, storytelling, spiritual community, acceptance, and exercise. The vital importance of peer-to-peer support for dealing with and healing from moral distress was highlighted by all the nurses and allied health participants. The challenge of dealing with the rude, uncivil, and at times violent behaviour of patients and their families was felt by all the participants, who provided some harrowing accounts of what they face at the bedside. Constraints imposed by their College or regulatory body were identified by a number of participants as contributing to the experience of moral distress. This was felt so severely by the clinical chaplain she declined to register as a regulated psychotherapist.

Because the HCPs in this study understood their values and obligations differently, their moral distress was both an individual experience and a situational experience. Thus,

moral distress as a form of suffering is both a universal experience for the HCPs on the long-term ventilation unit, and yet deeply personal. It remains unknowable, and it many respects untreatable, until it is shared with another human being. Ideally this sharing is with others who know the suffering you speak about. As in 12 Step spirituality when one alcoholic shares with another, the identification of one HCP with another HCP can be the portal that opens the heart for healing.[354]

Peer-to-peer support has been shown to be a powerful force for healing for both those practicing 12 Step spirituality and those HCPs suffering moral distress. Morley provides some concrete steps for applying this support in the hospital **(Figure 9).**[115]

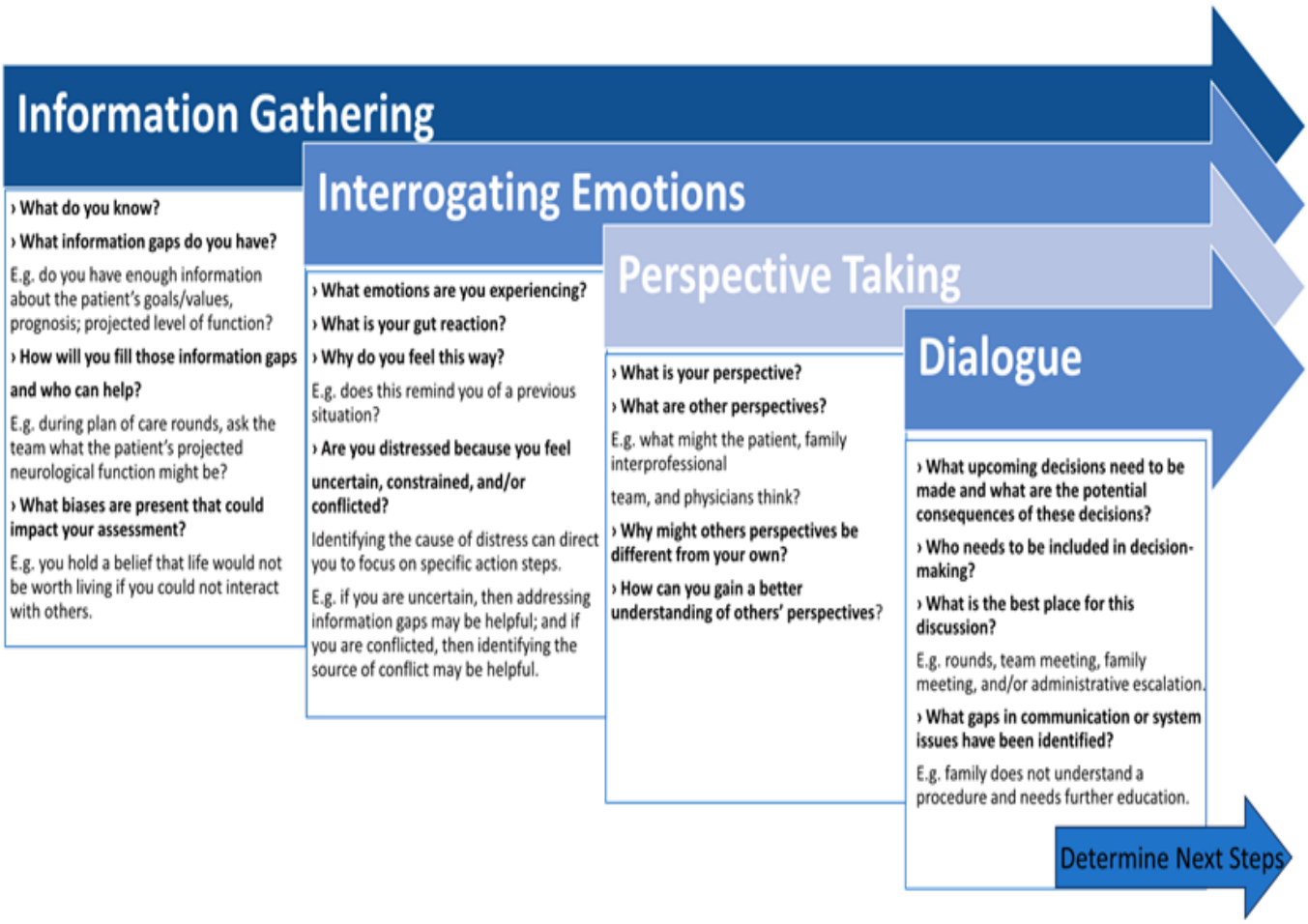


Figure 9. Moral Distress Peer Support Navigator Tool

It will be important for peer-to-peer support to be effective that one is mindful of potential barriers to its successful implementation. Some of these issues include… “a lack of anonymity; lack of trust in peer supporters’ qualifications, experience, or ability to maintain confidentiality; concern that the mental health of the peer supporter is just as poor as theirs; the belief that they didn’t need peer support; not knowing how to access the program; changes to their peer supporter mid-issue; and the rank or tenure of the peer supporter.”[355(p52)]

This research has shown that the frequency, intensity, and duration of moral distress on the long-term ventilation unit, appears proportional to the frequency, intensity, and duration of the relationship between HCP and patient. It would make sense that the more time I spend with another, and the closer I feel to another, the deeper I will experience any emotions that the relationship may generate, and the more responsible I will view my self for any perceived harms. Those HCPs who are left to administer directly at the bedside, in temporal and physical proximity to their patients, will suffer the greatest moral distress. The further removed one is from the consequences of one’s actions the less one may suffer. The less power and autonomy to follow one’s conscience, the greater the opportunity for moral distress.

What then could be a solution to this. Obviously we cannot grant all HCPs the power to do as they see fit in the moment. We are oftentimes not aware of all the facts. At present there does not appear to be a better model for the modern day hospital than the hierarchical medical model we currently have in place. To minimize epistemic injustice we must ensure that, as much as reasonably possible, all the multidisciplinary team are aware of the rationale for potentially morally distressing situations. Moral distress may occur when HCPs are not informed of treatment decisions and their views are not valued in decision-making or multidisciplinary rounds, creating ‘epistemic inequality’ on the long-term ventilation unit.[356] They may not all agree, but we must have multidisciplinary team rounds where respectful and curious enquiry and sharing of professional opinions are encouraged. Though the HCPs may be powerless then to change the direction of a decision that they disagree with, they will not feel helpless and unheard, as many may still do.

Ongoing education of patients and family members requires a multidisciplinary approach, appreciating the differing learning styles and cultures, and the application of distinct methods for the evaluation of knowledge.[357] Importantly the HCPs require training to learn these skills so they can effectively administer patient and family education.[357] It is in this area that a monthly ventilator support group (VSG) could prove helpful in providing pertinent education to patients and families. There is good evidence which confirms the effectiveness of support groups for patients and families.[358,359,360,361,362,363] The VSG adds a personal dimension to the care of ventilated patients by addressing the needs of body, mind, and spirit. The primary objective of a VSG would be to provide information and education, emotional support, and offer a safe outlet for expressing feelings.[364] Ideally the VSG would be facilitated by the unit spiritual care chaplain or unit social worker, as they will already have the trust of many of the patients, families, and staff. As a VSG is a relatively unique undertaking, it may also provide an opportunity to study its effectiveness.

The social worker highlighted issues with the “Home First” philosophy. The “Home First” philosophy was introduced in Ontario a decade ago and was in response to hospital patients being discharged to a long-term care home (LTCH) before a home discharge was fully explored. While the philosophy was well intentioned, with the aim of reducing the strain on hospital beds and limited LTCH capacity and ensuring the best interests of patients, it was never intended to create a barrier when patients clearly required LTCH placement and there was no safe option for discharge to home.[365] Sarah highlighted the need to center our patients more in their care and have more active conversations where patients and families are able to self-determine their discharge journey. Putting patients and families at the center of their care and helping them to determine their care pathway is recommended.

From the testimony of those who toil at the beside on the long-term ventilation unit it is clear that overall the support they receive from each other, clinical management, and senior leadership is good. Practice makes progress, and the following recommendations, borne from the HCP’s direct personal experience and the literature, are offered for consideration.

5.2. Summary Recommendations

5.2.1. Organizational / Unit

- Improved awareness of the availability of the Ethics Consultation Service for all HCPs. Simplify the process for initiating a request for ethical support at the bedside. Encourage all professions to avail themselves of the assistance an independent ethics service can provide.

- Provide training for Ethics providers in the nuances and differing assessment a moral distress consultation, as opposed to an ethical dilemma, may require. Education on the important difference between powerlessness and helplessness. If the HCP has a religious or spiritual worldview then guiding them from a passive state of helplessness to powerlessness can be achieved by their faith. For those of an agnostic or atheistic outlook a secular explanation of the positive benefits to acceptance of present moment reality ought be considered. Training in radical acceptance may improve their ability to implement both emotional acceptance and cognitive reappraisal.

- Continued support for the “Code Brew” service provided by Spiritual Care.

- Facilitated debriefs following challenging cases of ventilator withdrawal, Code Blues, and unexpected deaths.

- Continue the culture of supporting and encouraging diverse perspectives and be comfortable when HCPs challenge the prevailing narrative. The HCPs must feel safe that they will not be marked out as “troublemakers” for their respectful dissenting opinion or highlighting of concerns.

- Establishment of a monthly ventilator support group (VSG), for patients and their families. Overall facilitation of the VSG by a regulated health professional with training in psychotherapy. Monthly expert guest speakers e.g. Behaviour Support, Respiratory therapy, Physician, Social Work etc.

- A minimum, recurring period be set (and whenever there is a significant change in the patient's condition) for all long-term ventilated patients to have the multidisciplinary team reassess their goals of care and resuscitation status. Any concerns or disagreements from the team would trigger the involvement of the Ethics Service.

- Assess the feasibility of a best practice "behavioural wing" for long-term patients with behavioural issues which negatively impact staff at the bedside. Apply for the Provincial funding that would be required. The wing to be staffed by nurses and other HCPs with specialized training in caring for patients with behavioural challenges. Staff would apply to work on the unit and be eligible for relocation breaks to other less challenging and distressing units when needed. Patients would be under the care of a specially trained multidisciplinary Behaviour Support Service.

- Improved and rapid access to mental health support for patient's families

- Provide the time and resources for some regulated HCPs on the long-term ventilator unit, such as RNs and physiotherapists, for training in psychotherapy. Provide the time for these staff to then incorporate this practice into their daily work at the bedside, with both patients and relatives.

- Provide a more informed and participative role for patients, to improve their level of physical and psychological health on the long-term ventilation unit.

- Documentation burden is a significant driver of moral distress, particularly for nurses at the bedside. In view of the significant reduction to documentation burden that scribes and AI may provide, lobby the CNO to update their documentation practice standard (last updated 2008) and reconsider and clarify their position that documentation must be completed by the individual who performed the action or observed the event. i.e. consider following the position of the College of Physicians and Surgeons of Ontario.

- Implement computerized physician order entry (CPOE) to reduce errors, and thus, moral distress for pharmacists.

- The nearer patient admission decision makers are to the place that the decisions impact will reduce misunderstandings and misaligned expectations. Having the input of those at the bedside, and ventilator trained nurses dedicated to the admission process, will positively impact the pre-admission process for patients on long-term ventilation.

- Center our patients more in their care and have more active conversations where patients and families are able to self-determine their discharge journey. Putting patients and families at the center of their care and helping them to determine their care pathway is recommended.

5.2.2. Personal

- Facilitated peer-to-peer support group for the long-term ventilation unit staff. Time limited facilitated group interventions have been shown to be an effective tool to improve the mental health of HCPs and reduce their symptoms of distress. Use this safe environment to bring staff's personal pandemic experience to light and provide time for staff to express their grief, frustration, confusion, and sadness in a healing space.

- Morley provides concrete actions steps **(Figure 9)** which may be implemented on the unit to provide peer-to-peer support or to facilitate self-reflection for nurses experiencing moral distress. These steps may mitigate the sense of helplessness that is often associated with moral-constraint distress.

- From 12 Step spirituality we are given the insight that it is ok to be powerless so long as one does not believe themselves helpless or without hope. Teaching HCPs the experiential and conceptual difference between powerlessness and helplessness in moral distress will be of vital importance. It will require time and education for HCPs to become comfortable with the knowledge that for the most part they are powerless over much of what happens in the hospital. It is ok to be powerless and it is healthy to accept their powerlessness, just so long as they have help and hope.

- For our HCPs reporting a significant moral injury and shame consider providing Acceptance and Forgiveness Therapy (AFT).

- Provide education and support so our HCPs can identify, process, and heal from the various traumas they experience in their daily work on the long-term ventilation unit. To achieve this our HCPs need the resources to be aware of the symptoms and available treatments, and management ought to support staff to decrease their workloads, encourage leave, increase supervision, and provide any necessary spiritual and mental health resources.

- For the nurses on the long-term ventilation unit continuing education and support for dealing with grief ought be provided.

- Mindfulness / meditation sessions to be provided for staff at times they can attend.

5.2.3. Future Research

- No AI was used in any part of this thesis. Research Ethics Board approval for a comparative summary analysis of the research findings will be requested, for potential publication in a peer reviewed journal. This will compare and contrast an AI generated analysis, using NVivo© AI and/or Open AI, with the already developed human analysis. Will a post-hoc AI analysis of the data complement the human analysis and be considered non-inferior to human only analysis?

- In respect to the phenomenon of moral distress, what are the particulars, differences, and characteristics of powerlessness, helplessness, and hopelessness? How might we empower our HCPs to help them move from a negative state of helplessness to a healthy acceptance of powerlessness?

- Why are staff not asking for help? Is it timidity, fear of asking questions, or that they don't know they don't know?

5.3. Limitations

A limitation (and strength) of this research is its focus solely on a long-term ventilation unit. Also, these interviews were conducted at the end of the pandemic, which had a significant impact on the testimony shared by the HCPs. Though ten participants are the recommended number for a doctoral IPA study, it would be unwise to confidently

extrapolate the individual experiences and analysis of HCPs on a long-term ventilation unit to other healthcare sectors. Furthermore, one cannot be confident that the experience of one HCP from a specific profession accurately mirrors their peers working in other areas.

5.4. Conclusion

Moral distress is an emergent phenomenon and not a first cause. Its development is highly influenced by the ethical and supportive climate of the workplace environment. Moral distress is a perfectly natural response of our conscience to doing or saying something we believe is wrong. Providing the rationale for why the HCP must say or do something is a vital first step in mitigating the negative sequelae of moral distress. We ought to give our HCPs tools and practices for healing from moral distress and strengthening their moral resilience. Principles and virtues such as acceptance (Steps One & Three), faith and hope (Step Two), honesty (Step Four), courage (Step Five), willingness to change (Step Six), humility (Step Seven), forgiveness (Step Eight), patience and prudence (Step Nine), self-inquiry and reflection (Step Ten), mindfulness and meditation (Step Eleven), and loving-kindness in action (Step Twelve) are helpful.

However, often the first cause is organizational and so this will not be enough. I can brush my teeth and floss to prevent cavities and take painkillers and antibiotics when I get an infected tooth, yet until the first cause, the infected tooth, is removed there will be no resolution. This truth was highlighted by multiple HCPs in this study who continued to feel the pain of moral distress, flowing from having to action unreasonable and/or unnecessary medical care, until the physician was let go. This highlights the necessity of an ethical and supportive work environment with full multidisciplinary conversations and collaboration. For our treatment to be truly effective we must deal with the root causes of the moral distress. For example, until we prevent our nurses from being used as… “someone’s emotional punching bag,” they may continue to leave.

This study has explored the phenomenon of moral distress, through an interdisciplinary research lens, looking at the whole multidisciplinary team caring for patients requiring long-term ventilatory support. These HCPs were drawn from the disciplines of nursing, clinical management, medicine, pharmacy, respiratory therapy, physiotherapy, spiritual

care, and social work. This study is unique in exploring moral distress in this population and environment. Throughout the text 12 Step spiritual principles and practices for potentially dealing with moral distress and healing from its sequelae were interwoven and explored. Moral distress is fundamentally both a spiritual issue and a psychological issue, and to package it only as a mental health problem does our HCPs a disservice.[37]

Due to the unique insights provided by the lens of 12 Step spiritualty and virtue ethics this thesis provides a fresh and unique exploration of moral distress in healthcare. This thesis explored multiple professional perspectives from HCPs working on a long-term ventilation unit. I am indebted for the trust they gave me which allowed them to share with such honesty and courage. Ten HCPs from nursing, medicine, social work, respiratory therapy, physiotherapy, management, and spiritual care provided testimony that was rich, powerful, and furthers our understanding of moral distress in these various healthcare professions.

Evidence informed personal and organizational suggestions, based on the HCP's lived experience, are offered for dealing with and healing from moral distress.

This thesis uniquely uncovers and highlights the conceptual and experiential difference between powerlessness and helplessness as experienced by HCPs on a long-term ventilation unit. It will be vital that we understand these two concepts when discussing and treating moral distress in HCPs. Further research is required into how best we can differentiate between powerlessness and helplessness, and what are the appropriate modalities for dealing with these distinct phenomena.

This research contributes to the body of literature on moral distress in healthcare. It provides a new interdisciplinary perspective of moral distress, not only in nursing, but on the whole multidisciplinary team caring for patients in the homogenous environment of a long-term ventilation unit.

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Appendices

Appendix A. Bruyere Research Ethics Board Approval Letter

Bruyère

Contact the Research Ethics Office: REB@bruyere.org
Visit the REB Website: https://www.bruyere.org/en/researchethicsboard

BRUYÈRE RESEARCH ETHICS BOARD – APPROVAL LETTER

Date: 12 January 2023

Investigator Name(s): Mr. Paul McLoughlin

REB Number: **M16-22-063**

Study Title: ***An Explanation of Moral Distress in Healthcare Providers (HCPs) in a Long-Term Ventilation Unit***

Review Type: ☐ Full Board Review ☒ Delegated Review ☐ Administrative Review

Date of Approval: 12 January 2023

Approval Expiry Date: 12 January 2024

Dear Mr. McLoughlin,

Thank you for submitting the above noted study to the Bruyère Research Ethics Board for review. The study has been reviewed by the REB and approval has been granted. This study is approved until the expiration date noted above.

The following documents are approved:

Document Name/Title	Document Version Date
BREB	December 20, 2022
Informed Consent Form	December 15, 2022
Interview Guide	December 20, 2022
Questionnaire	December 20, 2022

No changes to, or deviations from, the approved documents should be initiated prior to submitting an appropriate amendment and obtaining written approval from the Research Ethics Board, except when necessary to eliminate immediate hazard(s) to study participants.

An Annual Renewal must be submitted a minimum of 30 days prior to the date of study expiration if the study will continue beyond the expiration date.

If the study is completed by the expiry date noted above, a Study Closure report must be submitted to the REB.

Bruyère

Contact the Research Ethics Office: REB@bruyere.org
Visit the REB Website: https://www.bruyere.org/en/researchethicsboard

Sincerely on behalf of the board,

Kristi Wilde,
Research Ethics Manager

Signing for:
Gordon DuVal, SJD
Chair, Bruyère Research Ethics Board

The Bruyère REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans; the International Conference on Harmonization – Good Clinical Practice: Consolidated Guideline; the provisions of the Personal Health Information Protection Act 2004, and the Food and Drug Act of Health Canada and its applicable regulations.

Appendix B. St. Paul University Research Ethics Board Approval Letter

UNIVERSITÉ SAINT-PAUL UNIVERSITY

25-04-2023
dd-mm-yyyy

Comité d'éthique de la recherche (CER) | Research Ethics Board (REB)
Bureau de la recherche et de la déontologie (BRD) | Office of Research and Ethics (ORE)

CERTIFICAT D'ÉTHIQUE | ETHICS CERTIFICATE

SPU-REB Number 1360.42/22
Bruyère-REB Number M16-22-063

Last name	Name	Affiliation	Role
Mcloughlin	**Paul**	**Faculty of theology**	**PhD Candidate-PI**
Markwell	Hazel	Faculty of Theology	Thesis Director

Type of project Doctoral Thesis

Title An Interdisciplinary Exploration of Moral Distress in Healthcare Providers Caring for Patients on Long term Ventilation.

Approval date dd-mm-yyyy	Expiry Date dd-mm-yyyy	Decision (*)
25-04-2023	**24-04-2024**	**1 (Approved)**

(*) **Approved**:

The Research Ethics Board (REB) approved the project. Recruitment and data collection may begin as outlined in the application. Please use the **REB Protocol 1360.42/22**.
The ethics approval applies for one year. However, any modification to the project must first be approved by the REB before the changes can be implemented. The REB must be notified of all changes or unanticipated circumstances (Unanticipated issues / adverse events report) that have a serious impact on the conduct of the research, that relate to the risk to participants and their safety. An annual renewal report for ongoing projects must be submitted. The researcher must provide a final report for projects that have been approved by the Research Ethics Board (REB) in order to close all REB-approved files.

In accordance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 and other applicable laws and regulations, the Saint Paul University Research Ethics Board (REB) has examined and approved the application for an ethics certificate for this project for the period indicated and subject to the conditions listed above.

Ethics approval is valid for the period indicated above and is subject to the conditions listed in the section entitled "Special Conditions or Comments". The "Renewal/Project Closure" form must be completed four weeks before the above-referenced expiry date to request a renewal of this ethics approval or closure of the file.

Any changes made to the project must be approved by the REB before being implemented, except when necessary to remove participants from immediate endangerment or when the modification(s) only pertain to administrative or logistical components of the project. Investigators must also promptly alert the REB of any changes that increase the risk to participant(s), any changes that considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project or the safety of the participant(s).

Comité d'éthique de la recherche (CER) * UNIVERSITÉ SAINT-PAUL UNIVERSITY * Research Ethics Board (REB) *

Louis Perron, Ph.D.
Chair
SPU Research Ethics Board (REB)

Appendix C. Clinical Research Affiliate Confirmation

INSTITUT DE RECHERCHE
Bruyère
RESEARCH INSTITUTE

Adresse postale
Mailing Address
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6045
Téléc./Fax: 613-562-4266

Bureau central
Corporate Office
Tél./Tel.: 613-562-6045
Téléc./Fax: 613-562-4266

briirb@bruyere.org
www.bruyere.org/bri

September 9, 2022

Dr. Paul Mcloughlin
spiely@gmail.com

Dear Dr. Paul Mcloughlin,

Re: Bruyère Research Institute (Bruyère RI) Investigator Appointment

I am pleased to confirm your Bruyère RI appointment at the level of Clinical Research Affiliate. As per the Investigator Appointment policy, your appointment will be for a 3-year term and is subject to subsequent renewal. You are encouraged and will be supported to seek an academic appointment at an affiliated university (separate process) with approval to supervise graduate students.

As a Clinical Research Affiliate Investigator, you may have access to Bruyère patients, families, and residents for research purposes. You will be encouraged to participate in the academic life of Bruyère RI and may contribute to one of more priority research areas.

Space and resource requirements are based on availability, the amount of funding held with Bruyère RI, and specific needs of the research program. Space allocation will be reviewed on a semi-annual basis. Should there be a shortage of space; priority will be given to Senior Investigators who hold substantial funding at Bruyère RI.

The success and growth of Bruyère RI is dependent on our investigators and their contributions to increasing knowledge and understanding, building capacity, and providing solutions to improve health and health care for vulnerable populations.

Prior to accepting this offer, I ask that you review the attached Investigator Appointment Policy (IAP), Appendix A, the attached Bruyère Conflict of Interest Policy and Form, and the Guiding Principles – Working with Industry at Bruyère document - as they identify the responsibilities, privileges, and benefits of an appointment as well as specifics for reporting.

If you are in agreement, please sign and return page 2 of this document, as well as the attached Conflict of Interest Form.

If you have any questions, please feel free to discuss them with me or Trish DeFazio, our Senior Director of Operations.

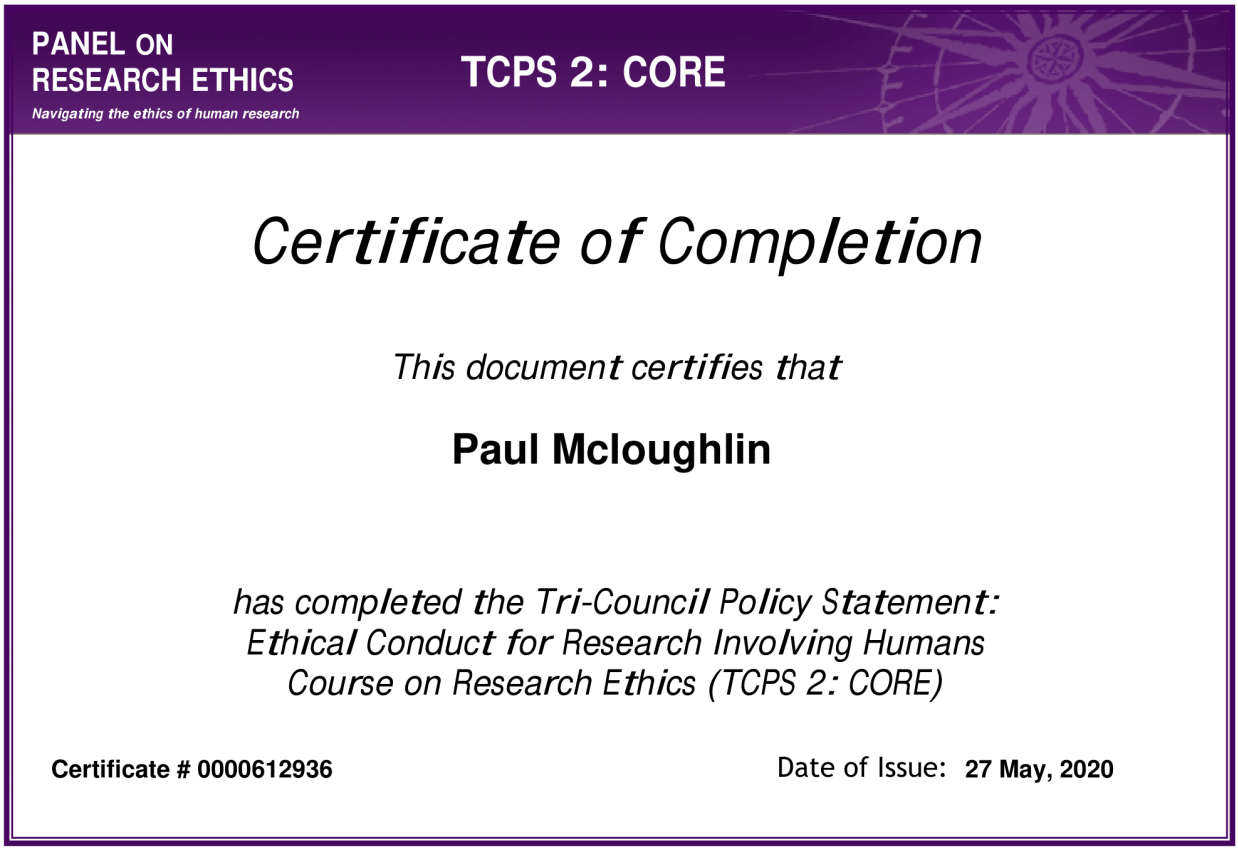
Sincerely,

Heidi Sveistrup, PhD
Chief Executive Officer and Scientific Director, Bruyère Research Institute and
Vice-President, Research and Academic Affairs, Bruyère Continuing Care

Affilié à / Affiliated with
uOttawa

La compassion et le savoir en harmonie
Blending Compassion and Knowledge

Appendix D. TCPS2:CORE-2022 Course on Research Ethics Certificate



PANEL ON RESEARCH ETHICS
Navigating the ethics of human research

TCPS 2: CORE

Certificate of Completion

This document certifies that

Paul Mcloughlin

has completed the Tri-Council Policy Statement:
Ethical Conduct for Research Involving Humans
Course on Research Ethics (TCPS 2: CORE)

Certificate # 0000612936

Date of Issue: **27 May, 2020**

Appendix E. Semi-Structured Interview Guide

Moral Distress Semi-Structured Interview Questions

We would like to express our gratitude for accepting our invitation to participate in this study. Over the next 1 – 2 hours, I will ask you some questions about your life history and experience of Moral Distress.

Thank you again for your willingness to participate in this study. I am recording our interview today. Do you consent to this recording, and do you have any questions regarding the recording?

Also, I want to remind you that you are not required to answer any question you do not want to.

Question 1: How long have you worked in healthcare? How long have you been in your current role?

Question 2: What attracted you to this type of work in health care?

Question 3: Think of a typical day here in the vent unit working with patients, families, and staff.

What would your day look like?

Question 4: Tell me about what the most challenging thing you do is and the most rewarding aspect of your work. As you know I am interested in understanding moral distress in healthcare providers. I am interested in hearing about your own experiences of moral distress.

Question 5: What do you understand as moral distress? (Moral distress can be defined as the suffering experienced as a result of situations in which individuals are aware of a moral problem, acknowledge moral responsibility, and make a moral judgment about the correct action to take, yet due to constraints (real or perceived) cannot carry out this action, thus believing that they are committing a moral offence by compromising their personal values. The suffering may present as feelings of anger, frustration, guilt and/or powerlessness associated with a decreased sense of wellbeing. Read out following participants explanation) Question 5: What is your reaction to this definition?

Question 6: I would like you to take a minute and think of some examples when you experienced moral distress? (Suggestive prompts: What was the situation? What was the feeling like? How did it affect you: time off work, personal ill health, frustration with self?

How was that different from other types of stress in your work? Where was the conflict for you? What made it morally difficult for you?

Question 7: Looking back at situations when you experienced moral distress, what did you find helpful in dealing/coping with moral distress? (Suggestive prompts: What helped you get through those times? Can you think of any practices, support?)

Question 8: Do you define yourself as a religious or spiritual person? Please tell me more about what spirituality and religion means to you. What was the role of spirituality, if any, on your experience with moral distress?

Question 9: What advice would you give to a healthcare provider for dealing with moral distress?

Question 10: Is there anything that I should have asked about your experience, but didn't?

Appendix F. Research Ethics Board Approved Participant Email

Hello,

My name is Paul McLoughlin, and I am a doctoral student working under the supervision of Dr. Hazel Markwell, Chair of Bioethics at St. Paul University, Ottawa. We are conducting a research study on moral distress in healthcare providers working on a long-term ventilation unit. Given your experience we feel that you may be well suited to provide insight into this topic and I would like to invite you to participate in this study.

If you decide to volunteer for this study, your participation will consist of a one-on-one semi-structured interview that will take approximately 60 - 90 minutes of your time, and a questionnaire that will take approximately 20 minutes. The interview will take place during your regular workday at . For nurses your patients will be fully covered by an extra nurse during the interview.

This study has been reviewed and received ethics clearance through the Bruyere Research Ethics Board and St. Paul University Research Ethics Board.

If you would like to participate, or you require additional information to assist you in reaching a decision about participation, please do not hesitate to contact me at pmcloughlin@bruyere.org.

Sincerely,

Appendix G. Consent to Participate Form

Research Ethics Board
(613) 562-6262 ext. 4003
REB@bruyere.org
Bruyère Research Ethics Board

RESEARCH INFORMED CONSENT FORM

Project Title: An Interdisciplinary Exploration of Moral Distress in Health Care Providers (HCPs) Caring for Patients on Long-term Ventilation

Version Date: April 26th, 2023, v1.4

Name and Contact Information of Researchers

Paul Mcloughlin, St. Paul University, Interdisciplinary Studies, Faculty of Theology
Tel.: 613-769-3742
Email: pmclo020@uottawa.ca & pmcloughlin@bruyere.org

Supervisor and Contact Information: Dr. Hazel Markwell, St. Paul University Chair of Bioethics, hmarkwell@ustpaul.ca Tel: 613-236-1393, ext.: 2454

Project Sponsor and Funder (if any)
N/A

Bruyère Research Ethics Board Approval

Date of Approval: January 12th, 2023
Study # M16-22-063

Invitation

You are invited to take part in a research project because you are a health care provider working with patients on . The information in this form is intended to help you understand what we are asking of you so that you can decide whether you agree to participate in this study. Your participation is entirely voluntary, and a decision not to participate will not be used against you in any way. As you read this form, and decide whether to participate, please ask all the questions you might have, take whatever time you need, and consult with others as you wish.

What is the purpose of the study?

Moral Distress may occur when the health care provider (HCP) knows the right thing to do, but institutional or other constraints make it nearly impossible to pursue this. Moral distress is associated with burnout, compassion fatigue, depression, errors in patient care, distancing from patients, and decreased job satisfaction. Moral distress has a significant impact at many levels: on the individual HCP, patients, the unit, and organization.
The purpose of this research is to develop an understanding of the lived experience, as it relates to moral distress, of HCPs working on a long-term ventilation unit. Due to the unique patient and environmental characteristics on a long-term ventilation unit, the HCPs experience of moral distress, and how you deal with moral distress, will have a distinctive flavour. This may

be crucial in developing effective remedies to the issue of moral distress and providing strategies for building moral resilience in Bruyere. One of the most significant predictors of a positive patient experience is the health & wellbeing of the people providing care to them - you. This research will aim to assist in developing healthy strategies to deal with moral distress, for you, and Bruyere Continuing Care.

What will I be asked to do?

If you agree to take part in the study, we will ask you to:

- Participate in a private interview with the researcher to discuss your experiences of moral distress. This will take approximately 90 minutes. This interview will be audio recorded and transcribed. The interview will take place in a private office at Hospital during a regular workday. For nurses, your patient assignment will be fully covered during the interview.
- The study will be in-person only. You must agree to the interview being audio recorded. Immediately following the interview, the recording will be transferred to a secure Bruyere server and deleted from the audio recorder.
- Approximately 1 week prior to the interview complete an electronic self-administered questionnaire that measures moral distress. This will take approximately 15 minutes and will be hosted on a private and secure Bruyere SharePoint site.
- There is nothing you need to do to prepare for the questionnaire or interviews.

Risks and Inconveniences

There is a chance that discussing your experience of moral distress may trigger some strong emotions. Your study involvement is on a volunteer basis and if at any time you feel that the questions or the process of the study are causing undue emotional distress, you can stop the interview or withdraw from the process. No explanation is required. You will have the option of resuming the interview at another time. You will be provided contact details for free confidential EAP psychological support. For secure file transfer we will be using DocSend, a subsidiary of DropBox, which houses data outside of Canada, and therefore there is an increased privacy risk.

Possible Benefits

You may not receive any direct benefit from your participation in this study. However, your participation may allow researchers to better understand moral distress and to Bruyere adopting practices that lead to healthy staff and workplaces.

Compensation/Incentives

You will not be paid or compensated for your participation in this study.

No waiver of your rights

By signing this form, you are not waiving any rights or releasing the researchers from any liability.

Research Ethics Board
(613) 562-6262 ext. 4003
REB@bruyere.org
Bruyère Research Ethics Board

Withdrawing from the study

If you withdraw your consent during the course of the study, all information collected from you before your withdrawal will still be used, unless you request that it be removed from the study data.
After the study, you may request that your data be removed from the study and deleted by notice given to the Principal Investigator (named above) within 3 *months* after your completion.

Confidentiality

We will remove all identifying information from the study data as soon as possible, which will be after the recording has been encrypted and transcribed by a professional who has signed a confidentiality agreement.
We will treat your personal information as confidential and confidentiality will be provided to the fullest extent possible by law - legally reportable information will be disclosed to the relevant authorities. Research records identifying you may be accessed by the Bruyère Continuing Care Research Ethics Board for the purpose of auditing the research.
The results of this study may be published or presented at an academic conference or meeting, but the data will be presented so that it will not be possible to identify any participants unless you give your express consent. De-identified data from this study may be shared with other researchers for verification, and to permit them to build upon our findings.

You will be assigned a code, or pseudonym, so that your identity will not be directly associated with the data you have provided. All data, including coded information, will be kept in a password-protected and / or encrypted file on a secure computer.
We will encrypt or password protect any research data that we store or transfer.

Data Retention

After the study is completed, your de-identified data will be retained for future research use, and retained for a period of 10 years and then securely destroyed.
.

New information during the study

In the event that any changes could affect your decision to continue participating in this study, you will be promptly informed.

Ethics review

This project has been reviewed and approved by the Bruyère Continuing Care Research Ethics Board as study # M16-22-063 and the St. Paul Research Ethics Board as study # 1360.42/22. If you have any ethical concerns about the study, or the way it is conducted, please contact the Bruyère Continuing Care REB: (613) 562-6262 Ext. 4003. Please note that during the time of the COVID-19 pandemic it is usually not possible to reach the REB staff by telephone. Accordingly, until more normal times, please contact the REB by email at REB@bruyere.org

Research Ethics Board
(613) 562-6262 ext. 4003
REB@bruyere.org
Bruyère Research Ethics Board

Statement of consent – print and sign name

I ___[*name of study participant*]_____, have read the information given in this informed consent and all my questions have been answered to my satisfaction. I have had sufficient time to consider whether to participate in this study. I understand that my participation in this study is voluntary and that I may withdraw from the study at any time without penalty.
I voluntarily agree to participate in this study.
I would like you to send me a summary of results from this study when they are available.
___Yes ___No
Email:_____

I agree to be audio recorded ___Yes ___No

_____
Signature of participant Date:

_____
Team member who interacted with the participant Date:

To the best of my knowledge, the information in this consent form, and the information that I, *(print name)* _____ have provided in response to any questions, fairly represents the project. I am committed to conducting this study in compliance with all the ethical standards that apply to projects that involve human subjects. I will ensure that the subject receives a copy of this consent form.

_____ _____
Signature of researcher Date

Appendix H. The Measure of Moral Distress – Healthcare Professionals (MMD-HP) Questionnaire[143]

Measure of Moral Distress – Healthcare Professionals (MMD-HP)

Moral distress occurs when professionals cannot carry out what they believe to be ethically appropriate actions because of constraints or barriers. This survey lists situations that occur in clinical practice. If you have experienced these situations they may or may not have been morally distressing to you. Please indicate how frequently you have experienced each item. Also, rank how distressing these situations are for you. If you have never experienced a particular situation, select "0" (never) for frequency. Even if you have not experienced a situation, please indicate how distressed you would be if it occurred in your practice. Note that you will respond to each item by checking the appropriate column for two dimensions: *Frequency* and *Level of Distress*.

	Frequency					**Level of Distress**				
	Never				Very frequently	None				Very distressing
	0	1	2	3	4	0	1	2	3	4
1. Witness healthcare providers giving "false hope" to a patient or family.										
2. Follow the family's insistence to continue aggressive treatment even though I believe it is not in the best interest of the patient.										
3. Feel pressured to order or carry out orders for what I consider to be unnecessary or inappropriate tests and treatments.										
4. Be unable to provide optimal care due to pressures from administrators or insurers to reduce costs.										
5. Continue to provide aggressive treatment for a person who is most likely to die regardless of this treatment when no one will make a decision to withdraw it.										
6. Be pressured to avoid taking action when I learn that a physician, nurse, or other team colleague has made a medical error and does not report it.										
7. Be required to care for patients whom I do not feel qualified to care for.										
8. Participate in care that causes unnecessary suffering or does not adequately relieve pain or symptoms.										
9. Watch patient care suffer because of a lack of provider continuity.										
10. Follow a physician's or family member's request not to discuss the patient's prognosis with the patient/family.										
11. Witness a violation of a standard of practice or a code of ethics and not feel sufficiently supported to report the violation.										
12. Participate in care that I do not agree with, but do so because of fears of litigation.										
13. Be required to work with other healthcare team members who are not as competent as patient care requires.										
14. Witness low quality of patient care due to poor team communication.										
15. Feel pressured to ignore situations in which patients have not been given adequate information to ensure informed consent.										

	Frequency					Level of Distress				
	Never				Very frequently	None				Very distressing
	0	1	2	3	4	0	1	2	3	4
16. Be required to care for more patients than I can safely care for.										
17. Experience compromised patient care due to lack of resources/equipment/bed capacity.										
18. Experience lack of administrative action or support for a problem that is compromising patient care.										
19. Have excessive documentation requirements that compromise patient care.										
20. Fear retribution if I speak up.										
21. Feel unsafe/bullied amongst my own colleagues.										
22. Be required to work with abusive patients/family members who are compromising quality of care.										
23. Feel required to overemphasize tasks and productivity or quality measures at the expense of patient care.										
24. Be required to care for patients who have unclear or inconsistent treatment plans or who lack goals of care.										
25. Work within power hierarchies in teams, units, and my institution that compromise patient care.										
26. Participate on a team that gives inconsistent messages to a patient/family.										
27. Work with team members who do not treat vulnerable or stigmatized patients with dignity and respect.										
If there are other situations in which you have felt moral distress, please write and score them here:										

Have you ever left or considered leaving a clinical position due to moral distress?

- ☐ No, I have never considered leaving or left a position.
- ☐ Yes, I considered leaving but did not leave.
- ☐ Yes, I left a position.

Are you considering leaving your position now due to moral distress?

- ☐ Yes
- ☐ No

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