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The use and misuse of moral distress in neonatology

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A B S T R A C T

The neonatal intensive care unit is recognized as a stressful environment; the nature of caring for sick babies with uncertain outcomes and the need to make difficult decisions results in a work place where moral distress is prevalent. According to the prevailing definition, moral distress occurs when the provider believes that what is "done" is not the right course of action, with an element of constraint: the provider has no choice but to act this way. This can lead to adverse outcomes, including burnout and a change of career. Traditionally, moral distress was considered to represent a misuse of power that forced nurses (typically) to provide burdensome treatments they believed not in the patient's best interests. Today, with shared decision-making, it is rare for physicians to act in a purely paternalistic fashion and impose management strategies on a team and parents. However, in the grey zones, it is not unusual for individuals with different values to disagree on a course of treatment. Healthcare professionals across all disciplines may feel constrained despite there being no identified misuse of power. We argue for a broader understanding of moral distress and an awareness that maladaptive responses to moral distress may result in "transference" of moral distress on to other healthcare professionals and even on to the families of babies for whom we have a duty of care. Strategies for dealing with moral distress exist. An appreciation of these dynamics will enable providers to reduce the negative impacts of moral distress while also using it as a vehicle for constructive discussion and progressive thought that will better serve our patients and our colleagues.

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1. Introduction

Moral distress is increasingly recognized as a significant issue within intensive care settings. It refers to the anguish experienced by a healthcare provider when he or she makes a judgement about what he or she should do but is unable to act accordingly due to constraints outside of his or her control [1,2]. The concept originally evolved within the nursing literature where misuses of power from medical providers are depicted as a key precipitant, resulting in aggressive care being enforced against a patient's best interests [3].

Today all healthcare professions are recognized as being impacted by the negative sequelae of moral distress, including burnout, threatened moral integrity, and leaving one's profession [4,5]. The constraints which limit healthcare providers' ability to act in accordance with their own moral preferences are broader and more varied than misuses of hierarchical power. In this article we argue for a broader understanding of the dynamics of moral distress, going beyond the idea of one healthcare professional as a victim of another's misuse of power. We argue that the historical notion of limiting 'constraints' to misuses of power has unhelpfully informed attitudes towards moral distress and has limited constructive responses to mitigate its harmful consequences. A greater focus on moral resilience and recognition of moral subjectivity will better enable healthcare providers to live with a degree of moral distress and use it as an impetus for medical decision-making.

2. Case study: baby Oliver

Baby Oliver was born at 23 weeks. Within the first week of life he developed a large bleed on one side of his brain. He has significant lung disease of prematurity and has required high ventilation settings and oxygen since birth. On day 12 of life he deteriorates further after developing an intestinal perforation and becomes critically unstable. His parents are counselled about his potential poor long-term neurodevelopmental outcomes, his critical state and the high risks of going to the operating room for surgery. The parents are offered end-of-life care, an expectant approach (knowing this probably would lead to death) or a surgical intervention that could also precipitate his death. The family opt for surgery. Jenny, the nurse who has been caring for Oliver the past three days, becomes distressed, believing it not to be in Oliver's interest to undergo a laparotomy. She believes the family has a very poor understanding of Oliver's current suffering and cannot possibly understand the impacts of his potential long-term poor neurodevelopmental outcomes. Nor does she believe that the parents have the capacity to provide the care he will need in the long term should he survive. Oliver is one of six children; his parents infrequently visit Oliver due to the needs of the other children and due to work. Jenny raises her concerns with Patrick – the neonatologist caring for Oliver. However, she becomes frustrated when Patrick informs her that the parents' informed decision needs to be respected. Jenny believes that Patrick "lacks what it takes" to redirect Oliver's care to comfort care. A unit debrief is arranged to discuss Oliver's case; however, Jenny decides not to go, saying "what's the point?" and choosing instead to "debrief" in the staff room with a couple of her colleagues.

Cases such as Oliver's are not unusual in neonatal intensive care units (NICUs). Though there is significant concern about his outcome by many involved in his care, there was sufficient uncertainty for the medical team to offer a laparotomy. His parents, who legitimately participated [6] in his decision-making, chose the intervention over comfort care. Among the healthcare team, however, there may be some who adamantly believe – due to different values, or a different assessment – that survival is not in Oliver's interests. These healthcare professionals are vulnerable to experiencing moral distress.

There has been much interest in trying to address moral distress, particularly within the nursing literature. Frequently, interventions focus on the idea of empowerment, which encourages the person suffering moral distress to access sources of power to initiate change or action or to resist what change is being forced upon them by a presumed misuse of power [7]. The problem with this approach is that it often encourages a "victim mentality" and oversimplifies the complex moral nature of treatment decisions in the NICU. Where empowerment creates an expectation for change, further moral distress may ensue: Jenny may become more distressed if she "fails" to change the situation.

3. Responding to moral distress

Let us consider the case of Oliver above in more detail. Jenny may respond to Oliver's case in three broad ways:

(i) Internalize her frustration and distress and not voice her concerns with Patrick. She may request to be assigned to another patient, or she may "debrief" with colleagues in the tea room by discussing the perceived "cruelty" or "torture" that is taking place.
(ii) Jenny may confront Patrick by telling him that surgical intervention is cruel and futile, and that thus they should attempt to change their management plan and inform parents that palliative care is the only option.
(iii) Jenny may initiate a discussion with Patrick that seeks to understand the ethically appropriate or permissible course of action (believing that her moral perspective is valid and important but that Patrick's is too).

The first option is clearly unhelpful. Jenny's moral distress goes unheard by Patrick. There is a missed opportunity to constructively discuss the case; furthermore her own moral distress becomes a source of division in the care team and contributes to the negative ethical environment in the unit. But the second is also not appropriate: it is based on the assumption that Jenny's moral position is correct, and that Patrick's is incorrect. Whereas this is sometimes true, it is often an oversimplification that empowerment literature may appear to support. Although expressing one's view is probably better than not advocating for one's patient, engaging in dialogue is better. There are several potentially competing moral values at stake and many subjective value judgments and important questions to ask. Is Oliver suffering? Is the surgery more likely to precipitate death? Would a drain at the bedside be a better option? If he survives, for how long? If he survives long term (with potential severe sequelae), is it in his interest? The situation is not as black and white as the second option implies. The third option enables

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