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ORIGINAL RESEARCH

Can the Ethical Best Practice of Shared Decision-Making lead to Moral Distress?

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Abstract When healthcare professionals feel constrained from acting in a patient's best interests, moral distress ensues. The resulting negative sequelae of burnout, poor retention rates, and ultimately poor patient care are well recognized across healthcare providers. Yet an appreciation of how particular disciplines, including physicians, come to be "constrained" in their actions is still lacking. This paper will examine how the application of shared decision-making may contribute to the experience of moral distress for physicians and why such distress may go under-recognized. Appreciation of these dynamics may assist in cross-discipline sensitivity, enabling more constructive dialogue and collaboration.

Keywords Decision-making · Neonatology · Clinical ethics · End-of-life issues · Professional–professional relationship

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Introduction

The concept of moral distress within healthcare originated within nursing literature, where it is reported to most commonly arise when nurses feel required to provide burdensome treatment which they regard as not in the best interest of the patient and feel powerless to act to the contrary. Although there is an increasing body of empirical evidence acknowledging the presence of moral distress in other healthcare professionals, including physicians (Hefferman and Heilig 1999; Solomon et al. 2005; Trotochaud et al. 2015; Wall et al. 2015), the nature and aetiology of this moral distress still requires exploration. Attending physicians are typically seen as key decision-makers and so it seems puzzling that their decisions and actions could be constrained in a way that leads to moral distress. Indeed, the usual scenario is the opposite of this: physicians' decisions are typically viewed as potential constraints and therefore sources of moral distress *to others*. This paper will argue that physicians can and indeed feel constrained in a way that causes them moral distress, and that the professional expectation to undertake shared decision-making is a key factor in this. Though shared decision-making is only one of many

types of constraints physicians may feel it is a useful place to begin a dialogue about physician moral distress.

The focus on physician moral distress in this paper should not be read as de-valuing the significance of moral distress experienced by nurses and other health professions. Nor is it intended to stereotype in terms of professional role or hierarchy. Rather, it is an attempt to increase understanding of this important phenomenon of moral distress by exploring the dynamics by which physicians can experience moral distress within the healthcare team. Physician moral distress is not more important than nurses' moral distress, but it may be somewhat different in its source and expression. A shared understanding of the nuances of moral distress may assist in improving intra-professional communication and the general ethical climate in hospital units—ultimately improving care for patients.

The Evolution of Moral Distress

The term *moral distress* was first coined by the nursing philosopher Jameton in 1984 (Jameton 1984). Along with Wilkinson, he refined the term to reflect the psychological distress that arises when an individual has a clear moral judgement about a specific practice but is prevented from responding accordingly due to societal or institutional constraints (Jameton 2013; Wilkinson 1988). Constraints can either be external (e.g. involving higher authorities, the law, or hospital administration) or internal—such as self-doubt, fear of job loss, or lack of courage (Austin et al. 2005; Wilkinson 1989; Hamric et al. 2012). We will focus on external constraints. While emotional distress of various types may be a common phenomenon within healthcare—providers are frequently exposed to illness, suffering, and tragedy—moral distress is distinct in that the distress is caused by the constrained moral response (Austin 2012a). Similarly, the term moral distress was intended to be distinct from moral dilemmas, wherein two or more conflicting moral principles apply but point to mutually conflicting courses of action (Jameton 1984). Though there have recently been some attempts to dissolve this distinction between moral dilemmas and moral distress (Fourie 2015; Campbell et al. 2016), here we will maintain Jameton's classical definition of moral distress. For though moral dilemmas may still cause some distress, the distress results from *moral uncertainty* or being *unsure* of how to act, rather than feeling sure that one is acting against one's moral convictions (McCarthy and Gastmans 2015). It is only the latter that threatens personal or professional integrity; a threat that is the hallmark of moral distress (Thomas and McCullough 2015).

Jameton later distinguished between two forms of moral distress: initial and reactive (Jameton 1993). Initial distress referred to the negative feelings of frustration, anxiety, and anger that ensue from feeling powerless to act in accordance with one's moral judgement. Reactive distress is the secondary distress or lingering negative feelings when one does not act upon one's initial distress; this is now more commonly called moral residue (Sauerland et al. 2014). It may result in long lasting regret or guilt (Jameton 1993). Epstein and Hamric (2009) further explored the relationship between initial and residue distress with what they called the crescendo effect. While initial moral distress may decrease following the passing of an event, the moral residue's lingering serves to increase the baseline for future moral distress. Over time, repeated crescendos are theorized to result in a growing moral residue, evoking stronger reactions in healthcare providers as they are reminded of earlier distressing events. This relationship of increasing moral distress with increasing experience is supported in a number of studies in nursing staff (Elpern et al. 2005; Epstein and Hamric 2009). However, it does not appear to be a universal phenomenon and in particular appears not to apply to physicians (Hamric et al. 2012). Chronic residue distress contributes to burnout and potentially leaving one's profession (Sundin-Huard and Fahy 1999): Sauerland et al. (2014) found that almost a quarter of nursing participants had left a position due to moral distress. Hamric et al. (2012) found a similar rate in the nursing profession and also found that 16 per cent of physicians had either left a previous position or were considering leaving a current position due to moral distress.

While there has been increasing appreciation that all disciplines within healthcare are susceptible to moral distress (Hefferman and Heilig 1999; Solomon et al. 2005; Trotochaud et al. 2015; Wall et al. 2015; Whitehead et al. 2015), there remains little empirical evidence about the interactions and team dynamics (Bruce et al. 2015) surrounding such distress. This is despite the recent moves to reconceptualize moral distress according to its "moral attributes" by linking the term to moral agency, integrity, and professional roles (McCarthy and Gastmans 2015). Though the distress may be experienced by an individual, it is shaped

> … not only by the characteristics of each individual (e.g. moral character, values, beliefs), but also by the multiple contexts within which the individual is operating, including the immediate interpersonal context, the healthcare environment and the wider socio-political and cultural context. (Varcoe et al. 2012, 56)

Professional Roles and Ethical Climate

The professional role of a physician or nurse comes with a *prima facie* duty to behave in certain ways and maintain a set of values within the cultural and traditional norms, respecting the trust that the public places in those roles. They are thus morally accountable to others including their patients, the institution for whom they work, their colleagues, and the broader public (Cribb 2011). The environment in which these roles and values are enacted is known as ethical climate.

Within the literature the accepted role of nurses is to provide bedside care of patients and their families (Cavaliere et al. 2010; Grundstein-Amado 1992b; Solomon et al. 1988; Grundstein-Amado 1992a; Walker et al. 1991). This care often involves working in close proximity with the patient and their family for prolonged periods of time, with little opportunity for relief in difficult or troublesome circumstances when compared to the physician who is required to attend to other patients and duties. Nurses are expected to act as strong advocates for their patients to prevent harm (Corley 2002), yet traditionally have less decision-making capacity (Hamric 2000) within the medical hierarchy. Furthermore they are often the agents carrying out the specified treatment plan. Moral distress accounts have their roots in this distinction of roles, with the combination of medical hierarchy and intensive medical therapies a common source of distress to nurses seeking to fulfil their perceived duty. The distress may be particularly acute when their perceived duty is to provide compassion and enable patients to die with dignity and the medical decision is to continue intensive life-sustaining treatment or further attempts at cure.

Similarly, the role of the "good doctor" or medical professionalism has been comprehensively described. Medical roles incorporate a variety of obligations as well as character attributes or virtues (Beauchamp and Childress 2001). Such virtues may include being compassionate, benevolent, honest and even self-sacrificial, placing the patients' needs above his or her own (McDougall 2013; Beauchamp and Childress 2001). A good physician should be attentive to the patients' needs, respect their autonomy and treat them fairly without prejudice (Tsou et al. 2013). He or she must balance the interests of the individual patient, their families, and the interests of wider society. Professionalism may require the physician to suppress his or her own emotions for the sake of the physician–patient relationship (Tsou et al. 2013). The good physician should not only be competent but also be committed to contributing to the advancement of knowledge and evidence-based medicine.

Medical Professionalism and Shared Decision-Making

The concept of shared decision-making encompasses many of these professional values and has become of central importance to the ideal doctor–patient relationship (Charles et al. 1997). Although shared decision-making is moving to a relationship between a team of inter-professional providers and the patient rather than a physician–patient dyad (Lewis et al. 2016; de Boer et al. 2012), we will focus here on the physician–patient relationship. This will allow greater conceptual clarity in analysing the basic phenomenon. Moving straight to shared decision-making within a multi-disciplinary team adds layers of complexity because non-concordance of opinion within the healthcare team can in itself be a source of moral distress (Bruce et al. 2015). It is however reasonable to think the discussion that follows could be extended to the team sharing responsibility for the medical decisions being made where there is unity within the team.

Traditionally, decision-making was the domain of the physician. He or she was expected to rely on his or her knowledge and wisdom to act beneficently and non-maleficently towards the patient; that is, to act in the patient's best interest. This paternalistic approach has since given way to an understanding that patients have a right to make judgements about what is the best medical treatment for them and are unique in being able to identify what is really in their best interests given that they will need to live the consequences (McNutt 2004). Shared decision-making arises from this broadened perspective. In shared decision-making the patient is no longer passive; rather, decisions are shared between

the physician and patient with the goals of ensuring that the patient receives the best-known treatment that serves his or her interests. The patient benefits from improved clinician–patient communication, knowledge, and risk assessment that encompasses an assessment of the patient's own values, goals, and circumstances.

However, the shared decision-making dynamic is more complex when the patient cannot decide for him or herself, as is the case for children or incompetent adults. For these patients, parents or family members usually act as proxy for the patients. Within this decision-making partnership there are greater limits to the proxies' decision-making power as a proxy's autonomous decision cannot be assumed to be equivalent to a patient choosing for him or herself. The decision-making "power" of the proxy is thus dictated by how closely the proxy's decisions align with the patient's known wishes (if previously stated/documented) or best interests where personal preferences or values cannot be known. The proxy's decision-making authority is furthermore limited by the principle of harm (Diekema 2004). That is, the physician may choose to honour the values and decisions of the proxy—even if considered suboptimal for the patient—as long as the patient is not subjected to probable harm (McDougall et al. 2016).

Yet in the case of a child, the patient's best interests are intrinsically linked with the interests of the family (in this case the proxy), complicating the shared decision-making dynamic. The child cannot live in isolation but can only be understood within the context of the family unit. Generally parents are assumed to be in the best position to know the interests of their own child (Katz and Webb 2016). (At times, however, the parents' and child's interests may appear to be in conflict, such as where the parents may not have the resources or support to be able to care for a child or where the parents wish to disengage from their duty to care for their child.) Physicians have an ethical imperative to care for and consider the needs of family in addition to the needs of the child (Jones et al. 2014) as i) promoting family's interests indirectly promotes the child's interests and ii) the family's interests have stand-alone moral weight. In general, having a good therapeutic alliance with the family better enables the physician to act in the patient's best interests while showing compassion and concern for the family's needs. The physician must ensure the family feel supported and not isolated in making critical decisions. Yet enabling families to participate in the decision-making process has been shown to improve families' satisfaction with end-of-life communication (White et al. 2007) and enable better grieving processes (McHaffie et al. 2001), enabling the physician to fulfil their broader duty of care to the family, even beyond the death of the child (Jones et al. 2014).

Though shared decision-making is central to medical professionalism, it can become complex to enact due to competing interests of those involved and due to the multiple aims it seeks to serve. We will argue that in certain situations shared decision-making, even though a key aspect of ethical practice in medicine, can be one of the external factors causing moral distress for doctors. We will focus on neonatal medicine as an example to illustrate this.

Shared Decision-making, Moral dilemmas, and Moral Distress

Before fully venturing into the effects of shared decision-making on moral distress, it is necessary to clarify how moral distress and an emotional reaction to a moral dilemma on the other hand, can be confused with each other, in situations where physicians are attempting to uphold their professional role in the neonatal setting.

In neonatal medicine, physicians and families must live with uncertainty. Some conditions, such as severe intraventricular haemorrhages, have very variable long-term outcomes published in the literature. Though a physician will discuss the probable outcomes of a given condition with a family, there will always be statistical outliers, neonates who do much better—or worse—than anticipated. In light of this uncertainty, physicians may face the dilemma of which treatment options are most appropriate. Together physicians and families must agree upon a management plan, acknowledging the dilemma of uncertainty while respecting the values of the family.

However, shared decision-making may also be a root cause of moral distress. A physician upholding shared decision-making by respecting the wishes of the family may feel compelled to provide medical care he or she believes is not in the patient's best interests, based on his or her assessment of the balance of benefits and burdens. In doing so the physician believes his or her actions to be morally wrong because the interests or views of the proxy have been placed disproportionately above the best interests of the patient. Despite having a duty of care to the family, the physician feels moral distress, believing they have acted wrongly towards their patient. The nature of this sense of compulsion to do what one believes is

wrong is complex and somewhat difficult to understand. The following case helps illustrate how this can happen.

Example

Ben, a preterm baby born at twenty-three weeks, develops severe necrotizing enterocolitis at two weeks of age. The surgeons perform a laparotomy where they determine that there is no viable gut. The neonate has significant lung disease and remains dependent on a ventilator. Additionally, the neonate has bilateral intraventricular haemorrhages and is already at significant risk for poor long-term neurodevelopmental outcomes. The treating team have recommended redirection of care: specifically, withdrawing the endotracheal tube while the child is in the family's arms and providing comfort until the baby dies. The family refuse and want to continue intensive care for their "little survivor." This would require keeping the neonate on a ventilator and providing total parenteral nutrition until an intestinal transplant could be considered. Such transplants are still considered largely experimental in their institution with only one known survivor. The neonate is critically unwell and the treatment team are in agreement that ongoing intensive management is only delaying death and prolonging suffering for the neonate.

The physician has formed the view that survival is not in this patient's best interests: the burden of intensive care is disproportionate. She knows that medical ethics supports the view that where burdens outweigh benefits, intensive care may be redirected towards comfort care. However, in upholding shared decision-making, she has decided that redirection of care will not occur for this patient until there is, at a minimum, assent (Payot et al. 2006*) from his parents, irrespective of how strongly she (or the rest of her team) consider that it is in the patient's best interests to die. While she believes keeping the baby alive is not right for the baby, she is concerned about adding to the grief of the family should she be unable to resolve the medical impasse. Additionally, she is concerned the institution will not adequately support her should the matter be taken to court. The societal expectation to not let children die, particularly when the parents wish to continue, weighs heavily upon her. Yet she knows the bed could be better used for many other babies awaiting beds in the unit. The physician is also aware that a number of the nursing staff are feeling distressed by the decision and the need to perform a number of potentially painful or uncomfortable procedures on the patient each day rather than allow him "to die with dignity." The physician has discussed the case extensively with other senior physicians within the unit, sought advice from the hospital ethics consultation group and arranged debriefing sessions for any team members impacted by the case. However she has not been able to resolve the tensions between the treating team and the family.*

Typically, a scenario like this will be presented as either a case of moral distress or a moral dilemma depending on whether it was presented in nursing or medical literature respectively. Yet this can be a case of moral distress for both professions. Within nursing literature, this type of scenario is one of the most common causes of moral distress within acute care—that is, being required to provide intensive, burdensome treatment which one believes wrong because of insufficient counter-balancing benefits and being powerless to act to prevent this because of the medical hierarchy (Austin et al. 2009). As described by Oberle and Hughes (2001), while physicians bear the burden of decision-making in the context of uncertainty, nurses must live with those decisions. There may be the perception that the role-defined "control" medical staff have over the situation as a result of being at the top of the medical hierarchy, leaves them free from constraints, safeguarding their moral agency and protecting them from moral distress. The nurse, in contrast, is presented as voiceless and ineffectual and must deal with the physical and psychological consequences of moral residue. Within this nursing literature an emphasis is often placed on the psychological and physiological consequences of the distress rather than the moral component of the judgements (Austin 2012b; Corley and Minick 2002; Epstein and Hamric 2009; Hanna 2004). In contrast, in the medical literature, little is made of the potential psychological or emotional response to these "dilemmas."

However, as this case demonstrates, physicians do not straightforwardly have full control; certainly not control they can exercise without consequences. So, rather than being a moral *dilemma*, we argue that the

above case should be regarded as an instance of moral *distress,* where the physician is constrained by the power of expectations of shared decision-making to the degree that they feel unable to avoid doing things to their patient that they (and likely many of their colleagues) believe to be morally wrong. This situation, we suggest, has arisen partly from the evolution of emphasis on the "shared" aspect of shared decision-making obscuring the limits of both shared decision making and the parents' legitimate (AAP Committee on Bioethics 2016) decision-making power. Where medical impasse occurs, the decision can no longer be truly "shared." Either the parents or the physician will feel constrained by the decision that is upheld, and potentially experience moral distress. Shared decision-making provides no satisfactory solution or way to move beyond the impasse. Assessing the balance of benefit and harm in such circumstances depends on value judgements, not just on matters of objective fact. Indeed, current practices therefore tend to lean towards favouring the family's judgement of what is in the child's best interests (Gillam et al. 2017; Albersheim et al. 2010) and overruling the family or proceeding to a court of law is generally discouraged (AAP Committee on Bioethics 2016). This leaves the physician feeling constrained to do what the parents want, providing treatment on the basis of the parents' values rather than their own. With increasing duration and intensity of suffering of the child, doing what the parents want tips the moral balance disproportionately against the interests of the baby, resulting in moral distress in medical and nursing staff alike. Here, the desire to continue with treatment until parents come to agree with redirection of care has been for the parents' interests and not the child. Given the disproportionate emphasis sometimes placed on the parents' perspective in shared decision-making, the physician may also fear that her colleagues and the institution will not support her if she acts against the wishes of the family for the sake of the child.

The physician may reason that with time and clear communication the family may agree to redirection of care to palliative care. However, multiple discussions may be required before the parents and the physician concur on the best interests of the child. During this time the child will likely have been subjected to some uncomfortable or burdensome procedures required to maintain physiological stability. Though the eventual outcome (that the baby dies) may be considered the morally appropriate outcome, both medical and nursing staff may be morally distressed by feeling that they are not (at least at that point in time) acting in the patient's best interests.

Though there often appears to be a continuum between moral dilemma and moral distress due to medical uncertainty, at some point the physician in the case above has clearly felt constrained by the obligations to practice shared decision-making and is distressed at not acting in the patient's best interests, meeting the classical definition of moral distress as described by Jameton (Jameton 1984). Shared decision-making has so strongly been aligned with medical professionalism and the expectations of patients and their families that the limits of shared decision-making are not so easily recognized within clinical practice. To make a seemingly autocratic decision in favour of the patient's best interests when shared decision-making is the norm, can psychologically feel to be going against role defined values, the culture of medical institutions, and the ethical imperative to care for the family. Shared decision-making can therefore act as a constraint for the physician in acting in the best interest of the patient and thus a source of moral distress for both medical and nursing professionals alike. The outward expression of moral distress may however differ between the two professions.

The Impact of Professionalism On the Recognition of Moral Distress

Medical professionalism has created an expectation for physicians to be in control of their emotions. This may mask the internal turmoil or "distress" of physicians. This was reflected in a small interprofessional qualitative study on moral distress within the ICU that found a contrast between the withdrawal or detachment of physicians to the "emotional investment" of nurses (Bruce et al. 2015). In light of literature that has initially focused on the psychological expression of "distress" of staff, it is not surprising that medical literature tends to use the language of dilemmas rather than *moral distress*. Lutzen's usage of the term moral stress (Lützén et al. 2003; Lützén and Kvist 2012) rather than distress may be a useful one in gaining a common language between medical and nursing staff, in addition to returning the emphasis to the

moral component rather than the psychological expression. Conversely, this may also miss the point that physicians can also be distressed despite having a different outward expression. Though the overt outward expression of moral distress may be limited in physicians, the threat to personal integrity and moral residue can still lead to disillusionment, clouding future decision-making and negatively impacting on patient care. There is no reason to believe that this distress should have any less impact on patient care than nursing moral distress; therefore it should be addressed in order to improve patient outcomes.

Why Acknowledging Moral Distress Within the Medical Profession Matters: The Challenge to Integrity and Moral Climate

Moral dilemmas may keep healthcare workers awake at night but shouldn't challenge personal integrity. Reasonable individuals may disagree about what a best course of action may be in uncertain and difficult circumstances. Though the decision remains a difficult one, each option is potentially of morally equivalent value. Moral distress, however, is the feeling that one has failed to act according to one's moral conviction. It strikes at one's integrity and threatens one's fulfilment of professional obligations to act in a patient's best interest. Lützén disputes this distinction, pointing to the fact that there is to date no evidence that moral distress causes a "different type" or intensity of distress than that caused by a moral dilemma (Lützén and Kvist 2012). However, to the authors' best knowledge, no empirical study has yet looked for this distinction.

Importantly, Repenshek (2009) questions whether many described cases of moral distress such as the case study above are better defined as discomfort with moral subjectivity rather than a real inability to act due to constraints. Here, discomfort with moral subjectivity refers to the distress that arises from conflicting personal values held by different moral agents, when there is no objective way of adjudicating between the differing views, rather than the distress that arises from being constrained to perform an objective moral wrong-doing. Others have used similar arguments to suggest we should dissolve the distinction between moral dilemmas and moral distress, arguing that one cannot be truly constrained if there is also reasonable disagreement about best interests (Campbell et al. 2016; Fourie 2015). Repenshek is correct that there is much moral subjectivity that underscores end-of-life decision-making in the neonatal intensive care unit, including but not limited to judgements of best interest. As implied by Weir, what is a moral dilemma to one may be a source of moral distress to another if they hold a different set of moral values (Weir et al. 2011). However, though there may be reasonable disagreement about what constitutes the best interests of a patient, for the person experiencing moral distress with a sincere belief that they are not acting in the patient's best interests, the phenomenon of moral distress is still very real. Thus it does not take away from the argument that physicians can experience moral distress due to feeling constrained by parental wishes—even if another physician would not experience moral distress in this situation but only a sense of facing a dilemma.

Conclusions

Moral distress must be addressed within the medical profession. Due to current conceptualizations of moral distress and medical professionalism—including shared decision-making—moral distress in physicians is potentially under-recognized in clinical practice. While the negative impacts of moral distress can be expected to be comparable between medical and nursing professionals, the outward expression of moral distress may differ. The professional behaviour of physicians often involves suppression of emotions and potentially withdrawing while looking after the potentially conflicting interests of the child, his or her family, and the staff caring for the child. With a traditional account of moral distress focusing on the outward emotional response, the distress of physicians may appear of lesser intensity and frequency when compared with the nursing population. Furthermore, the mostly widely used tool to measure moral distress—Corley's Moral Distress Scale (Corley et al. 2001)—was based on a limited conceptualization of moral distress and on research by and on nursing staff within predominantly adult acute care settings. Though modified versions have been created for paediatric populations and physicians, these were based on a small physician population and are known to have a reduced reliability in this setting (Hamric et al. 2012). Intervention programmes are now being

developed based on these limited conceptualizations despite a limited understanding of the nature and intensity of moral distress within physicians. These programmes have very mixed outcomes depending on the ethical climate of the institution (Hamric et al. 2012; Okah et al. 2012).

Acknowledging parents as a potential "constraint" is not intended to undermine their role in decision-making. The converse may in fact be true. Disillusionment with the decision-making process may encourage physicians to revert to conducting difficult end-of-life discussions in a more paternalistic manner in order to avoid similar distress in the future. Acknowledging and addressing moral distress may help to overcome physicians' fears and encourage physicians to engage families in the decision-making process, further enhancing the physicians' understandings about how to treat the patient and the family unit with care and compassion. Indeed, when shared decision-making works well, with physician and parents communicating openly and constructively, this can protect against moral distress in the physician.

A greater appreciation of moral distress within physicians may aid in creating a moral climate where concerns can be voiced and discussed in a constructive manner amongst healthcare providers. Moral distress may not reflect objective error or moral wrongdoing within the unit, when all things are considered, but does often reflect an environment where there has been insufficient ethical discussion that incorporates the views of all involved (Epstein and Hamric 2009). Nurses and junior medical staff must not feel alone in their distress. Acknowledging the moral distress of physicians and the constraints they feel may help to restore team unity rather than promote victimization. Moral distress should be a flag for collaboration of opinions and an opportunity to clarify where ethical permissibility lies (Wilkinson et al. 2016; Thomas and McCullough 2015). It can be a reminder that all members of the team are working towards the same goal of upholding the best interests of the patient, even when that goal may require patience, taking time to achieve. Collaboration, especially in culturally diverse units, will enable exploration of value systems and enable a broader conversation with parents.

While societal expectations of physicians' roles may change, the physician–patient relationship is likely to always remain central to medical professionalism. Recognizing and addressing the impact of this relationship on moral distress within the medical profession may go some way to improving ethical climate and ultimately patient care.

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