



Editor's Forum

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What is the meaning of moral distress? How does moral distress differ from other distressing experiences encountered in clinical practice? Is moral distress in and of itself a bad thing? Should we worry if we work in a clinical environment where no one feels moral distress? What strategies exist to address moral distress? In this issue of *Health Ethics Today*, researchers and clinicians address moral distress in contemporary health care. The articles are based on presentations from the John Dossetor Health Ethics Centre symposium "Moral Distress: Caring for Those Who Care" held virtually on November 27, 2020.



In the first article of this issue, Wendy Austin and Daniel Garros begin by clarifying the meaning of moral distress as a human phenomenon. Situating moral distress in relational ethics, they explicate moral

distress as an embodied response to a perceived moral problem to which we feel constrained in our ability to act. They elucidate constitutive elements of moral distress through recourse to the literature and their own work within the context of critical care. From their article, we appreciate that sources of moral distress exist from the bedside to institutional

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levels. As such, any interventions that we hope respond to or otherwise address moral distress need to be multilayered in their approach. Recognizing our contemporary health care is complicated by a plurality of values and beliefs as well as budgetary and human resource constraints, moral distress is undoubtedly a perennial concern. We need to acknowledge its enduring existence and lasting effects.

Gary Frank explores the meaning of moral distress in the context of palliative care. We are reminded that palliative care is more than end-of-life care. It is a type of care that focuses on living with a serious illness. Palliative care is not a stranger to moral distress as this care takes as its focus relieving all sorts of suffering: physical, psychological, social, and spiritual. In this article, Frank raises essential questions that health care providers need to ask, recognizing that there can be a temptation to turn towards palliative care as a solution for moral distress. Following, he urges us to consider how palliative care in and of itself can be distressing for health care providers as they confront their own mortality in caring for the dying and dead. The philosophy of palliative care is revealed as one ultimately focused on fostering a human relationship of presence, care, and connection.

Paul Byrne offers a reflection on the development and implementation of electronic health records (EHRs). While EHRs offer the promise of efficiency, safety, and other improvements, they have the potential to complicate the encounter of health care professional and patient/family. No area is perhaps more vulnerable to this disruption than the newborn intensive care unit (NICU). The NICU is, after all, where patients and their families face acute and/or chronic illness, a manifold of critical care technologies, and a team of hospital staff that can complicate the developing relation of parent and child. In place of the patient, the EHR can become the focus of attention not only by virtue of its physical presence, but also as health care professionals come to relate to the electronic construct of the patient that the EHR affords. Health care providers need to remind themselves to keep the patient/family foremost in their clinical practice.

Finally, Erin Burton and Chloe Joynt, on behalf of the Stollery Children's Hospital NICU CISM (Critical Incident Stress Management) Team, describe their experience of addressing moral distress in a high-acuity tertiary NICU. They describe their successful experience of building a CISM Team composed of nurses, physicians, respiratory therapists, social workers, and others that work within NICU. This team of health care providers was formed in response to an awareness of the frequent ethical moral complexities that arise when providing care to infants born extremely premature, with congenital malformations, and transitional problems such as birth asphyxia. The CISM Team received specialized training and backing from administration, enabling them to support practitioners on an individual level as well as broadly, to build a culture of recognition, resilience, recovery, and support. The effectiveness of this team has been evidenced by pre- and post-intervention surveys documenting improvements in staff perceptions of fatigue, peer support, resilience, and safety.

I hope the readers of *Health Ethics Today* take away from this issue that while moral distress is a contemporary concern in health care, its existence also reflects those practitioners' ethical engagement in the moral dimensions of clinical practice. In other words, when we name the emotional turmoil arising from our confrontation with situations that we feel constrain our acting for the "good" of a patient as moral distress, we acknowledge that we are ethically invested in the care that we offer. We bear ethical responsibilities for the wellbeing of our patients, their families, and our colleagues within and beyond our health care institutions. Now, clearly, we neither want to see ourselves nor our colleagues struggling, hurt, or otherwise psychologically affected through carrying out their professional responsibilities. But we do want practitioners who are engaged in the lives of those for whom they care. Identifying moral distress offers value to health care providers when we recognize that its presence can spur actions, interventions, or other measures that benefit givers and receivers of health care.

“This isn’t right!”: The Call to Moral Responsibility and Its Intrinsic Challenge, Moral Distress

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Our understanding of moral distress is situated in relational ethics—an understanding of ethics that locates morality within interpersonal relationships. In this brief article, we address the component elements of moral distress and suggest responses based on our own and others’ research. Experiencing moral distress as a healthcare practitioner (HCP) can be incredibly impactful. Research participants speak of being *haunted*, of *failing*, of feeling *ashamed*. A sense of failure can reshape one’s self-image as a capable and ethical person. Healthcare professionals endure sleepless nights from experiences that occasion moral distress—even when such incidents happened years ago. The COVID pandemic has contributed to significant moral distress among HCPs, making the topic a pressing one.

The research on moral distress has evolved significantly since its first descriptions in the discipline of nursing. The definition we use is: the embodied response of an individual to a moral problem for which the individual assumes some moral responsibility, makes a moral judgment about the appropriate ethical action to be taken but, due to real or perceived constraints, participates by act or omission in what they regard as moral wrongdoing (Jameton, 1984; Nathaniel, 2006; Wilkinson, 1987-1988).

Embodied Response

We may recognize an ethical issue by the sick feeling in our gut or, as a nurse participant in our PICU moral distress research put it: “the hair on the back of my

neck goes up ... oh, this doesn’t feel right” (Austin, Garros, Carnevale, & Frank, 2009). Our knowledge of the world is *embodied*. Antonio Damasio (2003, 2005), a neuroscientist, finds that there is no pure rational thought separate from the body. Feelings occur in the mind and the body. It is not mind over body, objectivity over subjectivity: our responses are integrated. Sociologist Zygmunt Bauman (2002) claims that emotions and feelings are the drivers of moral action, our response to the other before us. Mental health practitioners describe reactions of tension, concern, anger, anxiousness, even fear when the ethical action was “the least worst thing” that could be done or decisions seemed not in a patient’s or family’s best interest: “part of me is shriveling up;” “it breaks my heart ... it’s not right to make them suffer so much;” “what have we done?” (Austin, Bergum, & Dossetor, 2009). And yet we need to acknowledge that our emotions, including distress, are a key component of professional judgment.

Moral Problem

Philosopher Arne Vetlesen (1993) describes *receptivity* to ethical issues and *sensitivity* to the moral domain of practice as preconditions to moral performance. A moral problem must be recognized or it does not exist for us. This truth is revealed by psychiatrist Robert Jay Lifton (1988) when describing the Nazi genocide: physicians framed actions, such as organizing the death of disabled infants, psychiatric patients, and others, as public health measures. Nurses who took part described acting with obedience and compassion, like the nurse who

gently cradled her patient while she gave him poison, refusing to acknowledge to themselves the reality of their actions (McFarland-Icke, 1999). The perception of a moral problem is necessary to moral distress.

Moral Responsibility

Moral responsibility is central to healthcare practice. We live it. In Natalie Ford's study on crises of conscience of NICU nurses, a nurse described her first major conflict: "the insertion of a chest tube with no pain control on the baby's body . . . the doctor didn't believe they felt pain" (Ford & Austin, 2018, p. 996). Her repeated attempts to advocate for pain control failed. She felt a deep sense of personal failure: "(I felt) really sick to my stomach. I felt guilty. The major thing was guilt; that I was actually part of that situation. I felt I let that baby down. The whole family in terms of trying to get the best care that is possible for their baby" (p. 996). Participants in moral distress research usually begin their interviews with an unresolved experience that has stayed with them for years.



There are those who refuse to accept responsibility, employing what Bauman terms as "free-floating responsibility" whereby they believe that someone somewhere is responsible, but it is not them (Bauman, 2002, p.163). Another extreme example illustrates this. When self-denial of patient killings became impossible, some nurses still refused any moral responsibility. One said, "I considered the killings to be wrong. But I did not see that by transferring the patient into a different room or by helping to carry the corpses to the morgue that I was in any

way assisting with the killings. I did so because some superior had ordered me to do it. We, as caregivers, were taught to follow orders always" (Benedict, 2014, p. 127). Acceptance of moral responsibility is a key component of moral distress: a sense of responsibility animates ethics (Hatab, 1995).

Moral Judgement

The distress that practitioners experience occurs when, in their moral judgement, the action (or lack of action) undertaken is unethical, *not right*. Many elements form our moral judgement: upbringing, education, experience. Health ethics gives us language and frames of reference to use in making our ethical judgements. Practice experience is highly influential. In our research studies of moral distress of PICU teams, nurses shared that, at times, their strong conviction that a medical intervention is unethical was triggered by a sense of recognition and the feeling that something terrible was going to happen *again*. Such recognition may be informative to the clinical situation if one is able to share it with the team; it may generate a rethink of the therapy or a discussion of the issues. Being able to speak of one's misgivings and being heard can be sufficient to prevent one's passage into moral distress. Constraints on addressing our moral judgements in a meaningful way is the real problem.

What happens when, despite our moral judgement, real or perceived constraints mean that we participate by act or omission in what we regard as moral wrongdoing?

Consequences

Sustained suffering related to moral distress can evolve into moral injury: an erosion of confidence in oneself, in leadership, and in the system. The perceived loss of ethical integrity can diminish personal and professional identity. Following, therapeutic effectiveness may be compromised, and isolation from professional colleagues more likely. The moral injury to the HCP can lead to exhaustion and even the decision to leave the profession altogether (Shay, 2014).

Prevention and Resolution

Particularly during this pandemic, seeing patients dying alone, feeling remorse over visitation restrictions for which they had no voice, and witnessing hasty end-of-life decisions, HCPs felt that "...we cannot do what we know is best. Therein lies our distress" (Feltman, Moore, Beck, Siffermann, Bellieni, & Lantos, 2020, p. 233; Wahlster et al., 2021). Notwithstanding, moral distress can be a healthy sign, not a pathologic one. It involves trying to meet professional obligations and do the right thing, despite complex challenges and barriers (Canadian Medical Association, 2020). The coronavirus pandemic brought pressing and unprecedented challenges, but many HCPs felt proud of being part of the front-line, valuing the opportunity to respond with courage and skill and to learn and grow. Using one's skills and experience to respond to distressing situations is a way to mitigate moral distress (Rushton, Kaszniak, & Halifax, 2013).

At the personal level, to resolve moral distress, the concept of "communities of practice" becomes vital (Delgado, de Groot, McCaffrey, Dimitropoulos, Sitter, & Austin, 2020). To have others with whom to connect and share experiences can make a significant difference. It creates a means of speaking with one authoritative voice, such as respectfully demanding personal protection equipment, a good pandemic example.

At the institution level, leadership needs to validate the experience of moral distress, creating a sense of solidarity to sustain increasing pressures ("We are in this together," "We have your back"). Being honest and transparent about the situation when there are no answers or when more drastic measures are needed sustains trust, as does facilitating measures to enhance the wellbeing, physical and psychological, of the staff and creating opportunities for self-care (rest, hydration, meals, transportation).

Conclusion

Moral distress has gained significant importance as we practice in ever so challenging times and

settings. Recognizing its existence, acknowledging its impact on the well-being of HCPs, and facilitating its resolution has become a necessity in our healthcare institutions. By creating morally habitable practice environments, we can have the freedom to work safely, ethically, and with integrity.

References:

- Austin, W., Bergum, V., & Dossetor, J. (2009). Unpublished research data. Relational ethics in health care project: mental health care.
- Austin, W., Garros, D., Carnevale, F., & Frank, A. (2009). Unpublished research data. Moral distress of PICU teams project.
- Bauman, Z. (2002). *Modernity and the Holocaust*. Cornell University Press.
- Benedict, S. (2014). Meseritz-Obrawalde: A site for "wild euthanasia". In S. Benedict & L. Shields, L. (Eds.). *Nurses and Midwives in Nazi Germany: The Euthanasia Programs* (pp. 105-139). Routledge.
- Canadian Medical Association. (2020). *COVID-19 and Moral Distress*. Retrieved from: <https://www.cma.ca/sites/default/files/pdf/Moral-Distress-E.pdf>
- Damasio, A. (2003). *Looking for Spinoza: Joy, Sorrow, and the Feeling Brain*. Mariner Books.
- Damasio, A. (2005). *Descartes' Error: Emotion, Reason, and the Human Brain*. New York, NY: Penguin Books.
- Delgado, J., de Groot, J., McCaffrey, G., Dimitropoulos, G., Sitter, K.C., & Austin, W. (2020). Communities of practice: acknowledging vulnerability to improve resilience in healthcare teams. *Journal of Medical Ethics*, Epub ahead of print, Feb. 6, 2020. doi.10.1136/medethics-2019-105865.
- Feltman, D. M., Moore, G. P., Beck, A. F., Siffermann, E., Bellieni, C., & Lantos, J. (2020). Seeking normalcy as the curve flattens: ethical considerations for pediatricians managing collateral damage of coronavirus disease-2019. *Journal of Pediatrics*, 225, 233-238.
- Ford, N. J., & Austin, W. (2018). Crises of conscience in the neonatal intensive care unit: perspectives of Alberta. *Nursing Ethics*, 25(8), 992-1003.
- Hatab, L. W. (1995). Ethics and finitude: Heideggerian contributions to moral philosophy. *International Philosophical Quarterly*, 35(4), 403-417.
- Jameton, A. (1984). *Nursing Practice: The Ethical Issues*. Englewood Cliffs: Prentice Hall.
- Lifton, R. J. (1988). *The Nazi doctors: Medical killing and the psychology of genocide*. Basic Books.
- McFarland-Icke, B. R. (1999). *Nurses in Nazi Germany: Moral choice in history*. Princeton University Press.
- Nathaniel, A. K. (2006). Moral reckoning in nursing. *Western Journal of Nursing Research*, 28(4), 419-438.

Rushton, C. H., Kaszniak, A. W., & Halifax, J. S. (2013). Addressing moral distress: application of a framework to palliative care practice. *Journal of Palliative Medicine*, 16(9),1080-1088.

Shay, J. (2014). Moral injury. *Psychoanalytic Psychology*, 31(2),182-191.

Vetlesen, A. (1993). Perception, Empathy, and Judgment: An Inquiry into the Preconditions of Moral Performance. PSU Press.

Wahlster, S., Sharma, M., Lewis, A. K., et al. (2021). The coronavirus disease 2019 pandemic's effect on critical care resources and health-care providers: a global survey. *Chest*, 159(2),619-633.

Wilkinson, J. M. (1987-1988). Moral distress in nursing practice: experience and effect. *Nursing Forum*, 23(1),16-29.

Moral Distress in Palliative Care?

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Words themselves do not contain wisdom.
Words said to particular individuals at particular
times may occasion wisdom.
—Iris Murdoch (1970, p. 31)

Don't think. See.
—Bhante Henepola Gunaratana (2002, p. 42)

In addition to whatever else it may be, life includes all sorts of distress and suffering. Illness is one source of distress in life—and not only to the person who is ill. In recent decades the term “moral distress” can be found in the health care literature. What does it mean? What is the nature of the distress to which it refers? There is no consensus on how to define the notion of moral distress in health care, but one of the earliest and more commonly encountered descriptions is:

Moral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action. (Jameton, 1984, p. 6)

Examples of this type of distress in health care frequently describe situations in which aggressive interventions with little chance of benefit are seen to be a cause of significant suffering to the patient. But the “moral distress” described by Jameton does not refer to the suffering of the patient. It refers to

the distress of the patient's caregivers, often nurses, who feel powerless to change an approach to care that they perceive as detrimental to the patient's well-being. In such circumstances, palliative care is commonly considered as a remedy for this type of distress—and, indeed, it often is just that.

Palliative care focuses on comfort and making the best of whatever time is left to a person who has an incurable, progressive illness. Sources of distress in such situations include loss of ability to continue important activities, changes in human relationships and social roles, pain and other physical sources of discomfort, and the increasing proximity of death. These can combine to create significant suffering. Palliative care is an attempt by the community to alleviate such distress and suffering. Hence, if patients or caregivers feel that these causes of suffering are not being acknowledged, recognized, and addressed, or that aggressive and unhelpful interventions are exacerbating them, a desire for a palliative philosophy and practice of care may arise.

But if palliative care is one of the solutions to this type of moral distress, what is being referred to by the phrase “moral distress in palliative care”? There is much debate in the literature questioning whether the type of distress defined by Jameton in 1984 is the only thing being identified when the term “moral distress” is used in a health care context. Many

years after his initial definition, Jameton himself noted the wide range of contexts in which moral distress is now used (Jameton, 2017). Others have gone further and argued for a broader definition of the term itself (Fourie, 2017). My reflection on my practice and the relevant literature has led me to the following summary of potential responses to various ethical scenarios in health care: no distress because everything is perceived to be perfect; no distress because of no sense of responsibility for the situation (Tavris & Aronson, 2015); distress experienced because I perceive that I did wrong (this might be termed “a sense of guilt”); distress experienced because I perceive that other people, structures, or institutions did wrong (this might be termed “a sense of injustice”); and, distress experienced because I perceive that something is wrong, unfair, absurd, unjust, or unreasonably painful about life, death, the universe, reality, or a particular individual’s life experience (this might be termed a “crisis of meaning” or a “spiritual crisis”). These responses can, of course, occur in a variety of situations. The remainder of this paper will examine the types of distress encountered in palliative care and when they might be considered forms of “moral distress.”



The distress encountered in palliative care varies depending on the nature of the illness, the response of the person experiencing it, the reactions of those involved in the care of the ill person, and the care environment itself. Much of the literature on moral distress in palliative care relates to the burden on caregivers continually dealing with what is perceived as “unjustified” suffering (Rushton, Kaszniak, & Halifax, 2013). Exactly how various types of suffering can be compared or justified is unclear. But there can be other, quite different, sources of distress in palliative care that raise moral concerns for the practitioners involved. These often have to do with the problem of important but unacknowledged issues in a patient’s situation, the so-called “elephant in the room”—though the elephant may not always be what it is expected to be:

- Are palliative treatment options the only ones available? i.e. has the standard of care been offered to the patient for the disease in question?
- Is the patient (or agent) making informed decisions?
- Is the patient or caregivers (including professionals) “in denial” and, therefore, increasing the patient’s suffering with burdensome interventions unlikely to be of benefit?
- Is the use of resources just?
- “Why do the innocent suffer?”
- Death anxiety and ultimate questions of meaning in the face of mortality

There are several risks inherent in too readily turning to palliative care as a solution for moral distress. One of these is a potentially unjustified medical nihilism—a view that we should have little confidence in the effectiveness of medical interventions. Palliative care can provide significant relief from unhelpfully aggressive philosophies of care and the burdensome interventions they may entail. However, to determine what is a reasonable, ethical, and indeed, helpful approach to care, the current standard of care and

treatment for the disease from which the patient suffers must first be understood and clearly described by all involved. Anything less is sub-standard care and can lead a patient choosing a particular goal or philosophy of care based on inaccurate information provided by health care professionals. Besides, a nihilistic approach to assessment may also result in poor quality palliative care.

Practical examples of these consequences can include: assuming that serious infections should not be treated because there is “a mass” somewhere (i.e., insufficient work-up); not treating distressing seizures for fear it might prolong life; “over-treating” symptoms (e.g., inducing excessive levels of sedation). But why mention these possibilities? Of course, not all professionals are always thorough, and some can be blatantly incompetent or apathetic. These are serious ethical issues but what do they have to do with this paper’s topic: moral distress in palliative care? In some ways, they have nothing to do with this topic: most professionals are competent and caring. But medical nihilism can have a number of different causes, even when the professionals involved are exemplary practitioners. Professional burnout or exhaustion can impair clinical judgment, often unconsciously. Fortunately, more attention is being given to the need for self-care, and this problem is being addressed more effectively than it once was. Another possible cause of medical nihilism is loss of faith in the efficacy of a medical intervention in general, including palliative medicine. However, although some serious work has been done addressing medical nihilism (Stegenga, 2018), much work is still needed.

We are sometimes confronted with our own mortality—consciously or not—by facing the death and dying of another. This can be distressing. And it can be challenging to recognize the source and nature of this distress. Yet, health professionals need to gain insight into their own responses upon encountering dying patients:

If we do not understand the inescapability of our mortality, we are in a poor position to understand our own anxieties in confronting illness, our relationship to other people and

their suffering, and the way we think about the course and end of our own lives... We already misunderstand death if we think that a careful attention to the medical details of dying will nullify its menace to the self. Only a mastery of the self will do that for us, and only with great difficulty... (Callahan, 2000, pp. 143, 147)

We are morally distressed in palliative care because we are all, in the end, powerless in the face of death. This frightens us as humans and frustrates us as health care professionals who want to help alleviate our patients’ suffering. And, as Callahan (2000) says, the mastery of self that might allow us to deal with these realities wisely comes “only with great difficulty” (p. 147). Most of us are not saints or mystics. Is the situation, then, hopeless? No. For one thing, even a brief reflection to this aspect of our shared human condition reveals that it is just that: *shared*. In an era when we are faced with what seems to be an epidemic of irreconcilable differences, recognizing something as a shared human experience is essential:

We do not readily talk about how to shape our interior life in the face of death, because we think its meaning to be private, not easily shared or explored with others. Yet of course death is a universal human experience, and it derives its meaning as much from this universality as from the different circumstances of individual lives and deaths... Death makes all too clear that we are embodied selves... We might dearly like to deny that there is a fixed self embedded in a fixed body, that either possesses an inherent nature. Illness and death, however, will not allow that. Nothing could be more given... If we would like to reject all other notions of an essence of human life, to make up our own, that is one we cannot reject. (Callahan, 2000, pp. 129, 146, 154)

So, what’s a nurse to do—or anyone else? What is a wise and therapeutic response to the type of powerlessness we experience in the face of our own or anyone else’s mortality? How can we attain what some authors have termed “existential maturity”?

Existential maturity can be thought of as a state, stage, process, or ability in which death anxiety is coped with well. We think of it as a capacity in which people can appreciate our mortal condition without being overwhelmed by fear and loss. They can take in the goodness of life in a way that strengthens us even in severely disabled conditions. It is a fluid state rather than linear or static in that no one seems to simply “arrive and stay there,” but rather people oscillate within a range-of-feeling states. However, it is a reliable and recognizable state in that it allows a person to face mortality and do the work of dying and/or grieving without spinning out into panic attacks, traumatizing terror, or depression... a meeting presence is necessary; a present connection between the suffering person and someone. People tend to experience that kind of connection as love, but not always. In the personal setting, it may be love more often than not. In the psychotherapeutic setting, it may be transference love. Or in the medical setting, it is care but not love. Whatever we call it, once is usually not enough... (Emanuel, Solomon, Fitchett, et al., 2021, pp. 2, 5)



Whether we call this therapeutic human connection “love,” “presence,” “care,” or simply “connection,” what is clear is that a human relationship is necessary for it to occur. We cannot simply tell someone about it, or teach about it, or write about it. We must be it! That is, we must commit to engaging in realistic and reliable relationships of trust—relationships based

not on power but on a recognition of our mutual need to support each other in encountering our common human destiny.

I know what everyone wants
is a miracle.
This wasn't a miracle.
Unless, of course, kindness—

as now and again
some rare person has suggested—
is a miracle.
As surely it is.
—Mary Oliver (2006, pp. 63, 64)

References:

- Callahan, D. (2000). *The Troubled Dream of Life : In Search of a Peaceful Death*. Georgetown University Press: Washington, D.C.
- Emanuel, L., Solomon, S., Fitchett, G., Chochinov, H., Handzo, G., Schoppee, T., & Wilkie, D. (2021). Fostering Existential Maturity to Manage Terror in a Pandemic. *Journal of Palliative Medicine*, 24(2), 211-217.
- Fourie, C. (2017). Who Is Experiencing What Kind of Moral Distress? Distinctions for Moving from a Narrow to a Broad Definition of Moral Distress. *AMA Journal of Ethics*, 19(6), 578-584.
- Gunaratana, B. H. (2002). *Mindfulness In Plain English*. Wisdom Publications: Boston.
- Jameton, A. (1984). *Nursing Practice: the ethical issues*. Prentice-Hall: Englewood Cliffs, N.J.
- Jameton, A. (2017). What Moral Distress in Nursing History Could Suggest about the Future of Health Care. *AMA Journal of Ethics*, 19(6), 617-628.
- Murdoch, I. (1970). *The Sovereignty of Good*. Routledge: London.
- Oliver, M. (2006). *Thirst*. Beacon Press: Boston.
- Rushton, C. H., Kaszniak, A. W., & Halifax, J. S. (2013). A framework for understanding moral distress among palliative care clinicians. *Journal of Palliative Medicine*, 16(9), 1074-1079.
- Stegenga, J. (2018). *Medical Nihilism*. Oxford University Press: Oxford.
- Tavris, C., & Aronson, E. (2020). *Mistakes Were Made (but not by me): Why We Justify Foolish Beliefs, Bad Decisions, and Hurtful Acts*. Houghton Mifflin Harcourt: Boston.

Empathy and the Electronic Health Record

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The electronic health record (EHR) has become an integral part of clinical care. Its development, evolution, and implementation has been widespread over the past decade. In some jurisdictions, EHR use is legally mandated and is associated with financial incentives for physicians and hospitals. Studies attest to the improvements in quality, safety, and efficiency in clinical care related to EHR use (Sulmasy, López, & Horwitch, 2017). These improvements include faster communication and data transfer, better information retrieval, decreased error (especially medication error), and decreased missing records (the “lost charts” of yore). All of these benefits are hailed as providing a new level of “seamless care” for the patient resulting from the sharing of health information across different areas of health care delivery, including hospitals, clinics, and community-based programs. Several iterations of the EHR have been utilized in Alberta, and currently, EHR use is expanding.

Criticisms of early EHR design maintained that the EHR was overly system-oriented to maximize efficiency of information throughput with minimal attention to individual patients or practitioners’ needs. It was seen as another iteration of so-called managed care. Hospitals and large health systems were encouraged to acquire this technology to remain “state of the art” in terms of complex care delivery. Despite the need for a significant initial investment, EHR developers have been very profitable in selling their products and services.

Concerns have been raised about a “third person”—the computer—introduced into the traditional patient-physician dyad (Wright, 2015). Danielle Ofri describes being constantly distracted from her conversation with a patient by the urge to make a computer note in real-time or to “fact check” what the patient has just said. She writes, “Just give me a

minute,’ I’d beg of her, typing manically to catch up” as she attempts to remain engaged with the patient but not miss out on completing the required fields of the EHR (Ofri, 2019, p. 822).



In keeping with many health care professionals (HCP), Ofri (2019) believes that empathy is founded on the connection between the HCP and the patient. She asks how can we sense our patients’ world if we are “drowning” in the computer (p. 823). She cleverly illustrates this concern with two contrasting pictures: The first is the famous painting of *The Doctor* (1891, Sir Luke Fildes), showing the doctor sitting at a sick child’s bedside, wholly focused on the patient. This painting exudes empathy (and likely little autonomy and quite a degree of paternalism too). The second image is a crayon drawing done by a child in Ofri’s clinic showing the doctor typing on the computer with the patient and family present. There is no

empathy exuded here, but a high degree of shared information.

Empathy may be broadly understood as a capacity to cognitively and emotionally be there for the other person. Theodor Lipps (1851-1914) used the term *Einfuhlung* (feeling into) to describe a process of inner resonance, explaining how we become aware of each other's mental states. It involves imagining the other's situation, sensing it and trying to understand it. In addition, empathy requires an ability to communicate this sensitively (Halpern, 2014; Jeffrey, 2016). Empathy involves action and hard work!



In clinical care, this tuning to the patient's situation allows the HCP to provide care beyond simple diagnosis and treatment. Empathy has been recognized as essential for optimal care. It is highlighted in nursing education but less so in medical education. Empathy is somewhat at odds with the Oslerian traditional medical teaching of professional detachment or equanimity. These two connect due to the need for empathy to be limited professionally before the HCP becomes overwhelmed or risks burning out. There are many theoretical definitions and distinctions between empathy and compassion. Compassion may be regarded as

empathy plus action to help the other person. In clinical practice, there is an overlap between empathy and compassion (Jeffrey, 2016).

Ofri's (2019) paper made me consider the effects of the EHR in my own clinical world, the neonatal intensive care unit (NICU). The NICU is a space in which complex life-saving technology has acquired a prominent place over the decades. Staff in the NICU are used to machines, IV pumps, electronic monitors, alarms, etc., each directly related to individual patient care, and all of which require education and skill to operate.

But the arrival of the EHR introduced a different technology. This one also needs education, training and skill in the workings and uses of the EHR. Education includes attention to the ethical rules relating to privacy and confidentiality. Warnings about breaches of these rules feature prominently during orientation. In this respect, the EHR technology differs from the other NICU technology. In addition, the EHR is not solely directed at the individual patient.

The presence of the EHR physically amidst the clinical encounter, demanding our attention as it pops up endless results, menus, options, etc., distracts us from wholly engaging with the patient's (and family's) actual needs. We now have mobile computerized work stations on wheels (WOWs!) which are wheeled along on ward rounds and occupy a central position in the grouping around the infant and family. Almost every clinical discussion is punctuated by a back-and-forth self-interruption similar to Ofri's description. While the advantages of having a myriad of tests and results immediately available are evident in this NICU setting, a worry about disruption of that powerful, immediate empathic connection to the infant and family persists.

As part of an ongoing quality assurance program, we developed a simple questionnaire asking bedside nurses about their interactions with patients and families before and after the introduction of the EHR. The questionnaire was placed in the nursing lounge for three weeks. All answers were hard copy and anonymous.

The question asked was:

Do you think that by using the EHR on the bedside computer you spend *more time, less time, or the same time*, in caring and interacting directly with the baby and family than before the EHR was introduced?

There was an answer box to tick for each of the three possibilities. In addition, there was space to provide descriptive examples from the nurse's practice.

Forty six nurses answered of which 43 stated they had less time on direct care, 2 said it was the same time, and none said it was more time after EHR introduction. The comments were generally positive about the EHR in terms of data availability. But the requirement to "chart" electronically and stay current with EHR menu-driven results was seen as time-consuming and took the nurse away from the infant and the family.

Survey comment examples:

I find my time is about 50% less with parents. Too much to input (to EHR). It was easier to stand at the bedside and chat with parents and chart. Computers are distracting!

I feel I am more worried about charting than anything else. In any admission I'm thinking about charting.

Charting in itself is like another patient! It's frustrating to know I spend more time with the computer versus families / babies. This really saddened me and decreases our quality of care.

I can't hold babies and chart easily any more. Paper charting, I spent way more time in the room chatting with parents which was helpful.

We have way less time for patient care, teaching and communicating with parents and other NICU tasks (bathing, comforting, helping co-workers). I feel we spend too much time at the computer...I want to be with my babies / families more.

Many nurses describe relating closely to the infant and family as an essential part of their work with parents both when the infant is acutely ill after birth and later during the period of recovery. In the acute situation, the NICU nurse facilitates parental understanding of the infant's medical condition and education about its needs, including comforting and feeding. Many parents are in shock after an unexpected premature birth or complications of pregnancy. The bedside nurse's role in assisting the parents to cope with this sudden development is an essential part of good NICU care. Such close, frequent contact establishes the trust required to develop a healthy parent-HCP relationship in the early days of what often becomes weeks or months in NICU. In the less acute situation, over weeks or months, the needs of an infant and family change as clinical recovery and appropriate growth to be ready for discharge home become the focus. Ongoing involvement of bedside nurses who have come to know the parents well is key to optimal care at this later stage.

This simple questionnaire design does not allow it to show that the EHR caused a disruption in NICU nurses direct involvement with infants and families. But the consistency of the nurses' concerns points in that direction. This observation was distressing for those nurses involved and was attributed by them to the demands of "charting" electronically. They indicated that it did not reflect difficulty with the computers, their own skill level, or dissatisfaction with the EHR.

Their opinion was that the mandated EHR charting requirements compete for their time needed to develop a close relationship with the infant and parents. This is consistent with other reports from various clinical settings describing the shifting of the locus of care from the actual patient to the "electronic patient." In a time and motion study of EHR in NICU, inefficient tasks were eliminated, interruptions to tasks were decreased, communication was increased, but there was decreased frequency of contact with

the “patient zone” i.e., the bedside (Devin, et al., 2020).

Abraham Verghese (2008) eloquently describes this phenomenon as the “Flipped Patient” and the “Patient as Icon,” whereby medical residents are intimately familiar with all of the patient data before ward rounds but have not actually examined any patient that same morning. This may result in an electronic construct of the (as yet not examined!) patient based on admission history, transfer data, and ongoing results. In this situation, the patient (and family) likely has not been spoken to directly since admission to the ward. Verghese describes how for a generation of HCPs very familiar with the smartphone as an emotional support, there might be an assumption that the EHR is the dialogue with the patient, not a representation of one. The powerful hand-held data machine subsumes the clinician’s drive to speak directly with the patient. Unfortunately, the machine cannot tell us how well or how sick the patient is actually feeling.



In 1927, as part of an early American Medical Association study on patient care, Francis Peabody stated: “one of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient” (p. 877). Almost a century after that observation, the EHR is promoted as one among many extraordinary improvements associated with better health care. Yet, as measured more recent concerns of others about loss of empathy among HCPs, we need to remind ourselves that the human needs of patients must be foremost in our clinical practice.

References:

- Devin, J., Costello, J., McCallion, N., Higgins, E., Kehoe, B., Cleary, B.J., & Cullinan, S. (2020). Impact of an electronic health record on task time distribution in a neonatal intensive care unit. *International Journal of Medical Informatics*, 145(104307). doi.org/10.1016/j.ijmedinf.2020.104307
- Halpern, J. (2014). From idealized clinical empathy to empathic communication in medical care. *Medicine, Health Care and Philosophy*, 17(2), 301-311.
- Jeffrey, D. (2016). Clarifying empathy: the first step to more humane clinical care. *British Journal of General Practice*, 66(643), e143-145.
- Ofri, D. (2019). Empathy in the age of the electronic medical record. *Lancet*, 394(10201), 822-823.
- Peabody, F. (1927). The care of the patient. *JAMA*, 88(12), 876-882.
- Sulmasy, L.S., López, A.M., & Horwitch, C.A., American College of Physicians Ethics, Professionalism and Human Rights Committee. (2017). Ethical implications of the electronic health record: in the service of the patient. *Journal of General Internal Medicine*, 32(8), 935-939.
- Verghese, A. (2008). Culture shock—patient as icon, icon as patient. *New England Journal of Medicine*, 359(26), 2748-2751.
- Wright, A. (2015). You, me, and the computer makes three: navigating the doctor-patient relationship in the age of electronic health records. *Journal of General Internal Medicine*, 30(1), 1-2.

Critical Incident Stress Management Teams Realization, Refocus, and Resiliency in the NICU

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The Neonatal Intensive Care Unit (NICU) presents a unique picture of the uncertainty of welcoming a baby into the world. It breathes with life and sighs with death. It is fueled by hope and potential, but not without struggles for the babies, the parents, and the NICU team. The team is built of caregivers from varied disciplines (nurses, respiratory therapists, physicians, nurse practitioners and social workers) who understand the need for tenderness alongside strength and emotional intelligence to buttress scholarly knowledge with a focus centered on the caring for the infant and family. However, this understanding and attention infrequently extends to the care of the team itself. How is it possible that we can care so expansively for our patients but rarely acknowledge the need to care for one another with equal fervor? Why do some team members seemingly “cope” with an event of critical stress while others struggle? How do we build resilience in our team to “not be ok” and yet find strength and support to provide safe and compassionate care? To address these questions and build a construct to address this void within the NICU program, we have developed a Stollery NICU Critical Incident Stress Management (CISM) Team. This team aims to systematically and empathetically support those colleagues in need of “psychological first aid” while building a culture of team recognition, resilience, recovery, and support. In short, we have created a team that strives to *heal from the inside out*.

The Why:

Stress is a normal response to an abnormal event. Neonatal Intensive Care Unit health care providers deliver complex medical care to fragile infants and families suffering stress—moral dilemmas, rapid medical decompensation, death and conflict—all within an environment of high patient turnover, resource challenges, chronic noise, and emergency demands for critical performance level readiness. The pressures require extraordinary coping skills and resiliency. When events overwhelm “usual” coping skills, team members may falter and oscillate between confidence and insecurity, resulting in poor concentration, fatigue, change in self-esteem, emotional numbing, and burnout. Literature in the NICU demonstrates that caregiver burnout has “climate-like” associated with lower perceptions of patient safety culture (Profit, et al., 2014, p. 806).



In 2017, prior to the implementation of the CISM team, we surveyed our staff to understand the landscape of stress, resilience, and safety culture in our NICU. Ninety percent of staff surveyed felt they were positively influencing other's lives through their work, but 40% also felt that, at least once a week, they were fatigued by "getting up to face another day of work." Furthermore, 25% were taking sick time in response to an overwhelmingly stressful event as their standard coping mechanism. Only 60% felt they had little difficulty in "snapping back after something bad happened," whereas 74% agreed that they were less effective at work when stressed about an incident. These results paint a picture of professional pride inlaid with disquietude.

Naturally, staff rely on private stress relief systems: their friends, families, spouses, who undoubtedly offer a space for cathartic release but may lack insights or understandings of the pressures of working in a NICU. In comparison, while formal employee assistance programs exist, staff are unlikely to access these, unless critically impacted, due to the formal nature or perceived leadership-driven department. Only 38% surveyed in the NICU indicated that the current debriefing methods met their needs. While medical dimensions may get tackled in the traditional clinical debrief, event-impacts on people were typically completely overlooked. A middle ground was needed. What manner of support could offer both the tender touch of a known kindness in conjunction with training and resources for promoting effective coping? Who could offer the best support from a position of empathy and neutrality? With administrative backing at an arm's length (important in creating trust), peer support stood out as having all of these qualities, and thus, we sought to create a CISM team.

What is CISM?

Critical Incident Stress Management (CISM) is a structured peer support program facilitated by the International Critical Incident Stress Foundation (ICISF), offering individual and group crisis

management training. Commonly regarded as "psychological first-aid," it stands out as a process that encourages both individuals and groups to build resistance, foster resiliency, and find quick recovery through a process of restoring effective coping. It is not counselling, it is not fixing, and it is not feelings-based. Instead, there is a continual focus on the impact of an event and how one might move forward towards a healthy state of homeostasis. What armor did the individual/group already come in with? How can we reconnect that individual/group back to their "regular" coping?



After securing administrative support to fund and support peer champions, a steering committee, and CISM team members, a process of volunteer and peer nomination garnered applications for an interested team. Members agreed to a contract of two years, ensuring consistency and commitment. This contract contained a confidentiality clause, an essential aspect of the peer support team, intended to stop rumors and encourage a space for safe sharing and trust.

After three days of formal training by the ICISF, the team was ready to share their vision and make themselves visible. Roving education on stress and coping was an easy way for our team members to showcase themselves to the unit and build awareness about the team and its purpose while also beginning the

process of change adoption and building stress resistance. Pre-education is the back-bone of CISM because staff are “tapped into” self-awareness and what coping looks like for themselves. Further, the creation of official Terms of Reference, pamphlets, a call schedule, and a myriad of posters established us as a formal, approachable, and accessible means of support with clear guidelines for staff and unit administration as to what CISM was for as well as what it was *not* to be used for. If peer support is not enough, team members are trained to recognize their limitations and provide referrals. The CISM team partners with a psychologist to ensure staff members have access to appropriate additional support.

CISM at Work:

Given that the CISM team is composed of members who themselves work in the NICU (as peers), we are “on the spot” available. All an individual needs to do is ask for support (either for themselves or in response to a group who has experienced a high-stress event), and it will be provided. Importantly, all interventions begin with an assessment of the severity of impact. Critical Incident Stress Management is not intended for the individual/group who is coping well. In an attempt to avoid causing harm, the CISM team will not intervene if there is no need.

Once an assessment has been completed, an intervention is coordinated if deemed necessary through a “check-in” process. While the CISM team will organize a 1:1 for an individual in need, group interventions are more varied. Looking at the severity of impact, the team must recognize a homogenous group before exploring either diffusing/debriefing. More commonly, the Crisis Management Briefing (CMB) is utilized in an effort to provide factual information (by a key stakeholder) while also reinforcing the importance of self-awareness and care. It is through this process of reaching out and creating social connectedness that the CISM team supports resiliency. Acknowledgment and validation facilitate an understanding that heightened stress is simply a normal response to an abnormal event. By focusing on the impact of an event instead of the event itself, movement emerges towards knowing one’s own

coping mechanisms to find recovery. While the traditional clinical debrief can focus on the technical or medical events or team performance, a mind shift in thinking about the *impact* of the event on our team, facilitated by separate CISM interventions, heralds a holistic approach to the needs of a post-critical-event team/person.

Then and Now:

Through visibility, accessibility, and confidentiality, we have defined who we are as a CISM team within the NICU, and we have started to share our experiences with other units both within and beyond the Edmonton-zone. We have grown from our mistakes and surprised ourselves with unexpected victories. Most importantly, we have empowered one another to be kind and to feel safe in being inquisitive.

When re-surveyed in early 2019, a year after CISM implementation and 100 CISM activations later, only 27% of staff felt fatigued at the thought of coming to work (compared to 40% in 2017). Even though those surveyed felt that the workload had significantly increased by 2019, the number of staff that felt supported by one another increased from 59% to 77%.



More staff (71% vs 60% in 2017) felt they did not have a problem to “snap back after something bad happened” and the number of team members who felt that they were less effective at work after a stressful event decreased to 61% from 75%. More staff now felt the debriefing needs were being met (58% vs 38% in 2017).

Does this improvement in team resiliency and support affect patient safety? A 2014 study postulated that adoption of a CISM program

may serve as a mechanism for changing professional culture, thereby permitting the framing of even small incidents as an opportunity to provide valuable feedback to the system —Müller-Leonhardt, Mitchell, Vogt, & Schürmann (2014, p. 172)

In the 2019 post-implementation survey, 80% of staff (up from 66%) now felt secure and safe speaking up when they saw something negatively affecting patient care. A stronger team created a safer space for questioning and learning from each other’s mistakes.

Without a doubt, we have begun to see a unit that has adopted the principles of CISM. Our unit’s culture has flourished to one of general caring of its staff and its patients. All are more prepared to listen and to provide support to each important member of the NICU.

The Seed of CISM was planted and has now grown into a culture of caring.

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References:

- Müller-Leonhardt A. M., Mitchell, S. G., Vogt, J., & Schürmann, T. (2014). Critical Incident Stress Management (CISM) in complex systems: Cultural adaptation and safety impacts in health care. *Accid Anal Prev*, 68, 172-180.
- Profit, J., Sharek, P. J., Armspoker, A. B, Kowalkowski, M. A., Nisbet, C. C, Thomas, E. J., Chadwick, W. A., & Sexton, J. B. (2014). Burnout in the NICU setting and its relation to safety culture. *BMJ Qual Saf*, 23, 806–813.

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