society, and of recognising the limitations of aggressive medical treatment when death is imminent. Hospice and palliative care have enabled persons to maintain their autonomy and wellbeing at the end of their life cycle. This is due to the significant benefits of care that takes into account the person's values and priorities, which are often not restricted to just living longer.

Gawande argues that most aged care facilities do not sufficiently take into account their residents' priorities.3 Aged care facilities have the potential to make an important contribution to end-of-life care by providing holistic care that does consider residents' priorities. It is imperative to appreciate a person's priorities at the end of life as it respects their inherent dignity as human beings, and assists them in living a good life right to the very end.

#### **ENDNOTES**

Atul Gawande, "The way we age now," April 30th 2007, The New Yorker, http://www.newyorker.com/magazine/2007/04/30/the-way-we-age-now. See also Atul Gawande, "Letting go," August 2nd 2010, The New Yorker, http://www.newyorker.com/magazine/2010/08/02/letting-go-2.

Atul Gawande, Being Mortal: Illness, Medicine, and What Matters in the End (London: Profile Books, 2014).

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<sup>16</sup> Claire Spettell et al., "A Comprehensive Case Management Program To

Improve Palliative Care," Journal of Palliative Medicine 12, no. 9 (2009): 827-832 at 827, http://dx.doi.org/10.1089/jpm.2009.0089.

Being Mortal, 200-201.

<sup>18</sup> Ezekiel Emanuel and Linda Emanuel, "Four models of the physician-patient relationship," The Journal of The American Medical Association 267, no. 16 (1992): 1-9 at 2, http://dx.doi.org/10.1001/jama.1992.03480160079038. <sup>19</sup> Elisa Gordon and Christopher Daugherty, "'Hitting you over the head': Oncologists' disclosure of prognosis to advanced cancer patients," Bioethics 17, no. 2 (2003): 142-168 at 142, http://dx.doi.org/10.1111/1467-8519.00330. See also Walter Baile et al., "Oncologist's Attitudes Toward and Practices in Giving Bad News: An Exploratory Study," Journal of Clinical Oncology 20, no. 8 (2002): 2189-2196 at 2189, http://dx.doi.org/10.1200 /JCO.2002.08.004.

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<sup>21</sup> Jane Weeks et al., "Patients' Expectations about Effects of Chemotherapy for Advanced Cancer," New England Journal of Medicine 367, no. 17 (2012): 1616-1625 at 1617, http://dx.doi.org/10.1056/NEJMoa1204410.

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<sup>23</sup> lbid., 177–178. See also Alexi Wright et al., "Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death and Caregiver Bereavement Adjustment," The Journal of the American Medical Association 300, no. 14 (2008): 1665-1673 at 1671, http://dx.doi.org/10.1001 /jama.300.14.1665.

Being Mortal, 182.

<sup>25</sup> Ibid., 182–183.

<sup>26</sup> Robert Blank, "End-of-Life Decision Making across Cultures," The Journal of Law, Medicine & Ethics 39, no. 2 (2011): 201-214 at 204, http://dx.doi.org /10.1111/j.1748-720X.2011.00589.x.
<sup>27</sup> Centacare Brisbane, *Ten Principles of Catholic Social Teaching*, 2015,

http://centacarebrisbane.net.au/about/our-faith/. <sup>28</sup> Being Mortal, 249.

<sup>29</sup> Linda Emanuel and Karen Glasser Scandrett, "Decisions at the end of life: have we come of age?," BMC Medicine 8, no. 1 (2010): 57, http://dx.doi.org/10.1186/1741-7015-8-57.

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<sup>31</sup> Ibid., 245.

32 Ibid.

<sup>33</sup> Blank, 204.

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All online material accessed 16 July 2015.

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# **Moral Distress**

As health systems become more complex, moral distress is increasingly being recognised as a significant phenomenon amongst health professionals. It can be described as the state of being distressed when one is unable to act according to what one believes to be morally right. It may compromise patient care, the health professional involved and the organisation. Cumulative experiences of incompletely resolved moral distress—a phenomenon which is called moral residue-may leave us susceptible to more frequent and more severe moral distress. Clear open communication, respect, inclusivity, openness to differences, compassion, support, education and the capacity to grow in selfawareness are key aspects in minimising moral distress. Early recognition of its symptoms and addressing both personal and external constraints of actions can also minimise moral residue and build resilience to further distress.

Moral distress can be described as the feeling or state of being in distress when one is unable to act according to what one believes to be morally right. This 'morally right' conclusion is often framed by one's worldview, which incorporates values, experiences, knowledge understanding, and one's meaning and purpose in life. For example, the inability to inform a 12-year-old patient that she is dying because her parents forbid it, may cause moral distress in the medical team who believe the patient—even when young-has the right to know. Another example of what might cause moral distress is when a member of an executive team is compelled to abide by the decision of the whole team, even though the member believes that decision to be morally wrong or (at least) less morally right.

Unless addressed, the accumulation of such unresolved distress may lead to burnout, loss of self-confidence and selfesteem, chronic fatigue, social withdrawal and isolation, loss of purpose, physical illness, even leaving the workforce. Using the medical approach to illness—understanding the illness, primary prevention, recognition of symptoms and signs, investigation, management and secondary prevention (of further illness)—this article offers a framework for minimising moral distress and its adverse consequences. Whilst it is written in the context of healthcare, the approach could also be relevant in other fields.

## **Understanding Moral Distress**

Distress is one of the many emotions that may arise in the context of moral dilemmas or conflicts. Moral distress was first described in the 1980s in the setting of the nursing profession.1 Over the years, this phenomenon is being recognised in other areas such as business, finance and politics, and at all levels, from governance to grass-roots. Two related issues are at play: the moral dilemma or conflict, and the constraints both personal and external "that prevent one from taking actions that one perceives to be morally right."

Moral dilemmas often arise when there is a conflict between two morally obligated right actions such that each can be done but not both together.4 In the first example above, the medical team has an obligation to care for the child which involves truth-telling and transparency. This means informing her that she is dying, especially if she asks them directly, perhaps enabling her to live her dying days well and prepare for death. However, they also have an obligation to honour the wishes of the parents who are legally responsible for the child and who seek to act in what they consider to be her best interest.<sup>5</sup> These parents may believe strongly that informing their child of her prognosis would cause her to become deeply depressed. The dilemma of what to do may lead to moral distress for the medical team, especially if they believe that the obligation to tell the truth overrides any risk of depression that may ensue for the child.

Moral distress may be complicated further by personal constraints such as a lack of self-confidence and questioning one's own ability to discern. External constraints such as hospital policies and procedures, a refusal by management to listen, and a legal team enforcing parents' rights (possibly for fear of a lawsuit), can also aggravate moral distress. Conflicting cultural and religious beliefs, communication breakdown, resource allocation, institutional constraints, lack of receptivity to queries, and varying philosophical and moral orientations amongst health professionals are highlighted in the literature as additional factors contributing to moral distress.

## **Primary Prevention**

If conflicting moral obligations is the source of moral distress, it follows that resolution of that conflict would minimise, if not alleviate, this distress. Of paramount importance is clear communication with all involved regarding the facts of the illness and the treatment options. This also involves each party sharing with all concerned, the many reasons, both medical and moral, for choosing a particular action. Understanding the varying perspectives—especially that of the patient—alongside an attitude of openness to change, may result in a consensus.

Another consideration is the culture of the healthcare organisation. A culture which considers each employee only as a mechanical piece within a machine, to be discarded when non-functional or dissenting, would contribute to moral distress. On the other hand, a culture that considers each employee as part of and belonging to an evolving organization would contribute considerably to the prevention of moral distress. Employees who feel constrained from exercising their moral judgements for fear of repercussions would be encouraged instead to contribute to the moral integrity of the organisation through their questioning. The provision of support systems such as employee assistance programmes (EAP), ethics committees, critical stress debriefing, grief counselling, 11 approachable managers and mentors, and human resources personnel sensitive to the concept of moral distress, are most important.

In summary, then, the prevention of moral distress can be aided by: good communication amongst all concerned parties; attitudes of respect, inclusivity, openness and compassion, desiring only the good of the patient (and community); self-awareness, understanding one's own values and agendas, re-formulating them if appropriate, and not imposing them inappropriately on others; organizational flexibility and support; and genuine moral deliberation.<sup>12</sup>

## Symptoms and signs

Recognition of the emotions, particularly of distress, related to moral dissonance is the first step in the healing process. Psychological distress symptoms such as anger, anxiety, frustration, over-thinking, fear, guilt, withdrawal, fatigue, sleeplessness and physical ailments<sup>13</sup> may be attributable to other causes such as relationship difficulties, sudden death or being sued. However, these symptoms are a manifestation of moral distress when they are "the result of a perceived violation of one's core values and duties, concurrent with a feeling of being constrained from taking ethically appropriate action." Hanna proposes further that the harm is "tied to the intrinsic purpose of a person"—what one's purpose in life is—described by Aristotle as innately towards the good. It is important to distinguish the causes of distress as it helps determine the course of action.

Cumulative experiences of incompletely resolved moral distress—defined in the literature as moral residue<sup>16</sup>—may lead to the progression of emotional distress from loss of self-confidence, to loss of integrity<sup>17</sup> and identity, burnout, disenfranchisement, and significant ill-health.<sup>18</sup> Another outcome of the crescendo effect of unresolved moral distress and cumulative moral residue is the re-setting of one's threshold for moral distress to a lower level. This is described as the worsening of an individual's moral resilience which, in turn, can result in an increase in the number and severity of episodes of moral distress.<sup>19</sup>

The best path is to recognise its early signs. Moral discomfort for instance may include feelings of disquiet or uneasiness when considering the context or situation in which these feelings arise.

## Investigation

Having recognised these emotions, it would be important to note the facts of the situation and name the issues and values that appear to be contravened. Is this truly a moral issue or is it something else like, perhaps, a reaction to suffering? Is there a communication issue? Are the patient and family aware of all the facts: treatment options, prognosis, and illness progression or outcome? Is the discomfort or distress arising from conflicting subjective moral values—of self, other health professionals, patient, patient's family or organisation—or from ethical requirements related to the role such as patient advocacy?20 If it is the former, do we need to re-assess our own moral values and perhaps our worldview? If the latter, do we need to understand the reasoning behind the ethical requirement of the role in order to allay the discomfort or distress? Are the constraints for moral action internal or external to the individual? What are the opinions or teachings of experts such as ethicists, professional organisations, and other specialists? Do other colleagues feel the same, giving further credence to the moral conflict? Is any further information needed? Is there an underlying power-dynamic at play

between the health professionals, patient, family members, and/or the organisation?<sup>21</sup> Does this situation highlight unresolved experiences of past moral distress?

# The management of moral distress

Having both determined that moral distress is present and identified the issues contributing to it, the next step lies in discerning how to manage it at the personal, group (those involved in this particular situation) and organisational level. Communication of the facts of the illness, treatment options and prognosis, including different underlying values and beliefs, spirituality, past experiences and worldviews, may be a first step. It calls for an openness of mind and heart to this shared wisdom by those listening. A nonjudgmental and safe environment allows for venting of emotions and expression fears and vulnerability, which, in turn, are compassionately held by others. Once people feel heard and respected, conversations can begin, enabling each one to see different points of view and possibly shift their stance, leading to a consensus for the way forward. 22 Guidance from professionals such as ethicists is also encouraged. 23 The way forward may include reaching a compromise: owning what is one's personal morality without enforcing it on the patient; and/or coming to a place of not necessarily agreeing fully with everyone but being able to 'live with' the decision; being able to find meaning and purpose in the final outcome, making the decision acceptable. Understanding the context of and principles of decision-making in a particular incident may aid in transforming dissonance to harmony, and even, to acceptability, hence alleviating or resolving the moral distress.

At the personal level, the psychosocial aspects of moral distress need to be addressed. Seeking social supports from colleagues, trusted friends and mentors may aid in this. Assistance from professional organisations (e.g. medical or nursing) may be beneficial. The courage needed to take action begins with a commitment to address the moral distress in order to preserve one's "integrity and authenticity." Caring for the self is encouraged as a high priority. This includes addressing tiredness, vulnerability, feelings of isolation that may ensue. Utilising organisational resources such as counselling via EAP, clinical ethics services, ethics committee members, line managers or department heads, could be other avenues of support. Lützén and Kvist also propose an attitude of recognising moral distress as a "positive catalyst in exercising moral agency." 25

On rare occasions where no ethical resolution is foreseeable, the individual needs to discern whether they need to maintain their integrity and follow their informed conscience, 26 or to accept that the outcome is outside their control and that they have done everything possible to alert others to the moral wrong in play. The former may mean suffering some alienation and/or seeking employment elsewhere; the latter may result in compromising and letting go of responsibility, and in this way coming to some measure of peace within.

At the organisational level, recognition of the significance of moral distress amongst staff is a moral imperative. In this regard, worthwhile strategies include making resources available to those in distress: EAP; easy access to the clinical ethics service and/or ethics committee; clinical supervision whether internal or external to the organisation; and the education of both staff and human resources personnel on

moral distress. All these steps not only indicate a valuing of all staff but also help build a robust moral community.<sup>27</sup> The organisation could undergo regular reviews of policies and procedures according to outcomes of ethical dilemmas and investigations of staff moral distress.

# **Secondary Prevention**

As we recognise and grow in awareness of moral distress, secondary prevention involves ensuring that the issues which may lead to moral distress are addressed early. Enabling open communication at all times, exploration in an attitude of openness and respect of the values and beliefs of others that seem contradictory to one's own, and naming fears, are examples of what can be done as secondary prevention. The experience of moral distress often heightens the sensitivity to moral conflicts that may lead to another episode of distress. This sensitivity can alert one to address these issues and hopefully to resolve the conflict or dilemma before it escalates.

Building moral resilience is another aspect of secondary prevention. Monteverde suggests that moral resilience can be built with adequate moral knowledge, skills training such as communication and ethical decision-making, and promotion of attitudes such as "truthfulness, confidentiality, self-reflexivity, responsible scholarship."28 These aspects of moral resilience building can be exercised with each experience of resolving moral distress, and as Monteverde suggests, with healthcare ethics education. He warns however that moral resilience without outcomes of moral action or deepening of moral understanding can lead to moral apathy, burnout, even fanaticism.<sup>29</sup> Lützén and Kvist add another perspective of moral resilience in exploring Viktor Frankl's experience, defining moral resilience as "a concept that can be defined as a distinctive sense that life is meaningful under every condition."30

Making resources available for staff, as mentioned above, is another measure of secondary prevention. Included in these resources could be clinical ethics services, ethics committees with a consultative subcommittee, or, as suggested by Epstein and Delgado, moral distress consult services.<sup>31</sup>

### Conclusion

Moral distress is our Whole-Person way of recognizing that something is not right in the way we relate, or in our relationships within the environment in which we have our being. How we relate is based on our perspective and our expectations of ourselves and others. This in turn finds its roots in our values, belief systems, experiences, intuition, reasoning and knowledge. It is an evolving stance even as our interactions and relationships evolve, and therefore cannot happen in isolation. The proposal to exercise our moral agency through the perspective of the whole as well as the individual is an invitation to recognise that each has a share of the wisdom regarding the right moral act.

In the case of moral conflict and the distress that can arise from it, the opportunity for growth and true discernment lies particularly in our openness to listen to the Spirit through others. Ensuring open communication, adequate and appropriate resource allocation, staff support, ethics education, respect for each person involved—including cultural, religious, philosophical and moral differences—is a step towards minimising moral distress. Experts such as ethicists and clinical ethics services skilled in mediation may

assist in reaching consensus as to the way forward, or assist the individual in resolving their conflict. In some cases, allowing time and space for those involved to come to terms with what has happened may be all that is needed to comprehend fully the situation at hand and move forward.

Being conscious of the existence of moral distress, recognising the early signs, managing and resolving it, learning from the experience and putting into place strategies to minimise it in the future, at the individual, communal and organisational level, are necessary ways of diffusing this potential time bomb. It is yet another aspect of healing and whole-making to which we have committed ourselves as health professionals, and as human beings.

#### **ENDNOTES**

- <sup>1</sup> Andrew Jameton, *Nursing practice: The ethical issues.* London: Prentice-Hall, 1984. For a description of the evolution of the understanding and concept of moral distress since Jameton, see Kim Lützén and Beatrice Ewalds Kvist, "Moral Distress: A Comparative Analysis of Theoretical Understandings and Inter-Related Concepts," *HEC forum* 24, no. 1 (2012): 13–25 at 16–17. For a discussion of the definition of moral distress and a critique of the usefulness of Jameton's definition, see Debra R. Hanna, "Moral Distress: The State of the Science," *Research and Theory for Nursing Practice* 18, no. 1 (2004): 73–93.
- <sup>2</sup> Joshua E. Perry, "Managing Moral Distress: A Strategy for Resolving Ethical Dilemmas," *Business Horizons* 54, no. 5 (2011): 393–397. See also Markus Christen et al., "Measuring the Moral Impact of Operating 'Drones' in Pilots in Combat, Disaster Management and Surveillance," *Proceedings of the European Conference on Information Systems (ECIS)* 2014, Tel Aviv, Israel, June 9-11, 2014, http://aisel.aisnet.org/cgi/viewcontent.cgi?article=1160&context=ecis2014. Though focussed on the moral distress of drone pilots, this study can be extended to higher levels of political decision-making in political moral dilemmas.

<sup>3</sup> Elizabeth G. Epstein and Ann B. Hamric, "Moral Distress, Moral Residue, and the Crescendo Effect," *The Journal of Clinical Ethics* 20, no. 4 (2009): 330–342 at 331.

- <sup>4</sup> Terrance McConnell, "Moral Dilemmas," The Stanford Encyclopedia of Philosophy (Fall 2014 Edition), ed. Edward N. Zalta, http://plato.stanford.edu/archives/fall2014/entries/moral-dilemmas/. In #2, McConnell writes, "The crucial features of a moral dilemma are these: the agent is required to do each of two (or more) actions; the agent can do each of the actions; but the agent cannot do both (or all) of the actions. The agent thus seems condemned to moral failure; no matter what she does, she will do something wrong (or fail to do something that she ought to do)."
- <sup>5</sup> Hugo Gold, Georgina Hall, and Lynn Gillam, "Role and Function of a Paediatric Clinical Ethics Service: Experiences at the Royal Children's Hospital, Melbourne," *Journal of Paediatrics and Child Health* 47, no. 9 (2011): 632–636 at 634.
- <sup>6</sup> See also Elizabeth G. Epstein and Sarah Delgado, "Understanding and Addressing Moral Distress," *Online Journal of Issues in Nursing* 15, no. 3 (2010), endnote #3, http://gm6.nursingworld.org/MainMenuCategories /ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol152010/No 3-Sept-2010/Understanding-Moral-Distress.aspx.
- <sup>7</sup> Gold, Hall, and Gillam, 634. Although the article highlights common features of case consultations at the Royal Children's Hospital, it is likely that these cases resulted in sufficient moral distress in staff for them to seek the assistance of the clinical ethics service.
- <sup>8</sup> Barbara K. Redman and Sara T. Fry, "Nurses' Ethical Conflicts: What Is Really Known About Them?," *Nursing Ethics* 7, no. 4 (2000): 360–366 at 365.
- <sup>9</sup> This would include the healthcare team, the patients and their extended family members and loved ones.
- Two sessions are envisaged here: the first within the healthcare team, including each member of the team with differing views; and the second within the context of the situation, that is between the healthcare team, the patient or surrogate, the family and perhaps the ethics committee members.
- <sup>11</sup> American Association of Critical Care Nurses (AACCN), "Position Statement on Moral Distress," (Aliso Viejo, CA: AACCN, 2008): 1–3 at 2, http://www.aacn.org/WD/Practice/Docs/Moral\_Distress.pdf.

- <sup>12</sup> See Ibid., endnote #10. The concept of *moral deliberation* is an example of this process. It is described by Molewijk et al. as "a pragmatic-hermeneutical and dialogical" approach to ethics. It is a dialectical approach whereby the 'truth' is arrived at through reasoned dialogue. In this, the final conclusion may not be in keeping with the original opinions. Albert C. Molewijk et al., "Teaching Ethics in the Clinic: The Theory and Practice of Moral Case Deliberation," *Journal of Medical Ethics* 34, no. 2 (2008): 120–124.
- <sup>13</sup> American Association of Critical Nurses (AACCN), "The 4 A's to Rise Above Moral Distress," (Aliso Viejo, CA, AACCN, 2004): 1–11 at 3, http://www.aacn.org/wd/practice/docs/4as\_to\_rise\_above\_moral\_distress.pdf. Other physical, emotional, behavioural and spiritual signs of suffering are well-described and listed in this resource.
- <sup>14</sup> Epstein and Hamric, 331.
- <sup>15</sup> Hanna, 77.
- <sup>16</sup> Epstein and Hamric, 333.
- <sup>17</sup> For a further discussion on moral integrity and its complexities, see Lorraine B. Hardingham, "Integrity and Moral Residue: Nurses as Participants in a Moral Community," *Nursing Philosophy* 5, no. 2 (2004): 127–134.
- <sup>18</sup> Mary C. Corley, "Nurse Moral Distress: A Proposed Theory and Research Agenda," *Nursing ethics* 9, no. 6 (2002): 636–650 at 637. See also Hardingham, endnote #17.
- <sup>19</sup> Epstein and Hamric. See also Hanna.
- <sup>20</sup> Hanna.
- <sup>21</sup> Edison Luiz Devos Barlem and Flávia Regina Souza Ramos, "Constructing a Theoretical Model of Moral Distress," *Nursing Ethics* (2014): 1–8.
- <sup>22</sup> Molewijk et al.
- <sup>23</sup> Some organisations have a clinical ethics service whose function is "the provision of advice and support on ethical issues arising from clinical practice and patient care within a health care organisation." For more on this, see Anne Slowther et al., A practical guide for clinical ethics support (Oxford: The Ethox Centre, 2004), 6, UKCEN Clinical Ethics Network, http://www.ukcen.net/uploads/docs/education\_resources/ prac\_guide.pdf; National Health and Medical Research Council (NHMRC). Clinical Ethics Capacity Building Resource Manual, NHMRC, http://www. nhmrc.gov.au/guidelines-publications/e114?utm\_medium=email&utm\_ campaign=Release+of+the+Clinical+Ethics+Capacity+Building+Resource+ Manual&utm\_content=Release+of+the+Clinical+Ethics+Capacity+Buildin g+Resource+Manual+CID\_bd722f50dd92e39f20d2921eed113150&utm\_ source=Mailbuild&utm\_term=Clinical%20Ethics%20Capacity%20Building %20Resource%20Manual; and Catholic Health Association of the United States of America (CHAUSA), Striving for Excellence in Ethics: A Resource for the Catholic Health Ministry (Washington, DC: CHAUSA, 2009), 28-
- <sup>24</sup> AACCN, "The 4 A's," 2. This resource for critical care nurses may also be useful for those seeking to address moral distress. The approach of the 4A's is a cyclical one which involves Asking so that one is aware of the presence of moral distress; Affirming the distress and making a commitment to address it; Assessing the distress determining the source, severity and readiness to act; and finally taking Action and maintaining the desired change.
- <sup>25</sup> Lützén and Kvist, endnote #1. Lützén and Kvist further describe moral agency as "a multifaceted phenomenon beyond a single theoretical approach but can be regarded as consisting of moral knowledge, moral judgment and moral motivation, in which moral distress also plays a role." For this, see Lützén and Kvist, 22.
- <sup>26</sup> For a detailed understanding of what informed conscience entails, see Kevin D. O'Rourke and Philip J. Boyle, *Medical Ethics: Sources of Catholic Teachings*, 4th ed. (Washington DC: Georgetown University Press, 2011), 24–32.
- <sup>27</sup> Hardingham.
- <sup>28</sup> Settimio Monteverde, "Caring for Tomorrow's Workforce: Moral Resilience and Healthcare Ethics Education," *Nursing ethics* (2014): 1–13 at 4.
- <sup>29</sup> Ibid., 10.
- 30 Lützén and Kvist, 320.
- <sup>31</sup> Epstein and Delgado, 8.

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