

MORAL DISTRESS IN END-OF-LIFE CARE

During my recent sabbatical leave I investigated the important area of *clinical ethics*, and how such a service might be established and evolve at Ballarat Health Services. I visited clinical ethics services in hospitals and area health services in UK, Canada, USA and here in Australia (Sydney and Melbourne).

Clinical ethics, as opposed to research ethics, is concerned with the often complex issues that arise in day to day clinical practice especially in decision making about patient care. This could include helping with the resolution of dilemmas and conflicts that arise in the care of an individual patient through to organisational issues such as developing, implementing and reviewing policies which affect patient care.

One area of concern that repeatedly came up in my discussions with clinical ethicists both here and abroad was that of *moral distress* in health care. This phenomenon was first described in nurses in a book on nursing ethics by Andrew Jameton, an American psychologist & philosopher, in 1984 **(1)** and subsequent research has led to clarification and expansion of the concept.

Moral distress can occur when a clinician makes a judgement about what is morally/ethically the right thing to do in patient care but is prevented from pursuing that course of action due to constraints placed on them. These can be lack of time or personnel, lack of supervisory support or, most often, lack of “power” and input into decision-making due to a low position in the medical hierarchy. Nurses, junior doctors and medical students will usually feel powerless to challenge a senior doctor about their feelings and concerns and so are particularly vulnerable to moral distress.

Typically this might involve nurses (or junior doctors) who are directed by senior medical staff to continue life-preserving interventions in a patient who they strongly believe to be dying, and for whom they believe they are causing more suffering than benefit. They could also be prevented from providing palliative care interventions to relieve the patient’s distress and suffering due to lack of available medication orders or refusal of medical staff to provide them.

Moral distress has been well-described in medical students who, as part of their medical training, are obliged to observe or participate in examinations or procedures on patients that they feel are distressing to the patient.

It can also occur in aged care workers who may feel that they are limited in providing best possible care due to lack of human and other resources.

However it could also apply to a senior consultant, for example in ICU, who has a strong desire to admit a patient for intensive treatment but is stymied by lack of beds or other resources, or neonatal clinicians who feel forced, by parental demands, to continue what they consider to be futile treatment. So even those with higher places in the medical hierarchy can be frustrated and constrained by bureaucracy, policy and resource limitations.

Whilst end-of-life scenarios are not the only ones in which moral distress can occur within health care, they can be a particularly potent trigger for nurses in particular, due to the emotional stress involved in providing that care. Nurses, in hospitals and nursing homes at least, are the only health professionals who provide 24/7 care of sick and dying people, and so are highly invested in the appropriate care of that person.

Engaging in care that is contrary to their morals or values (e.g. continuing nasogastric feeds to a dying patient; not being able to intervene to relieve distress in a critically ill or dying patient with delirium etc.) is distressing and results in reactions such as anger, frustration, guilt, anxiety and resentment. If prolonged or repeated such distress can lead to longer term adverse effects in the nurse, such as emotional blunting, burnout and to resignation from the unit or from nursing completely. Moral distress leading to nursing staff attrition and impairment of psychological health are seen by all the ethics services that I visited as vitally important issues that must be addressed, as inevitably they have implications for optimal patient care.

Research has found that moral distress is often the result of problems with the nurse-doctor relationship. The following excerpt from a paper by Elizabeth Peter (Toronto) and Joan Liaschenko (Minnesota) sums it up well, I think.

“Nurses’ lower place in the hierarchy relative to physicians is thought to be underlying many of these problems, notably when nurses believe they have little influence over treatment decisions with which they disagree and when they believe their expertise is devalued. These conflicts often become most evident when nurses and physicians have opposing perspectives of what the best care and treatment for patients should be.” (2)

Of course, all health professionals, whether they be nurses, doctors or allied health staff, have their unique disciplinary knowledge and expertise to bring to bear on excellent patient care, so it is vital that all have the appropriate input into decisions about patient care, and not have it left to the old-style “follow doctor’s orders” approach.

In end-of-life situations what really bothers nurses, in my experience, is that despite their ‘around-the-clock’ involvement in patient care, their opinions about, and involvement with, patient care decision-making is either ignored or in some way discounted. As Reed and Rishel explain:

“...being active participants in interprofessional communication and collaboration is essential if nurses are to fulfil their responsibilities to the people they serve. Failure of the team to recognize the importance of the role of nurses in interprofessional collaboration can lead to poorer outcomes for patients and families as well as distress for nurses providing care.” (3)

A detailed account of how the prevalence of moral distress could be reduced in health care settings is beyond the scope of this article but suggestions have included:

- Education on clinical ethics to raise awareness of the stressors and triggers for moral distress.
- Supported reflective practice to help health care professionals better understand their own moral values and to open up dialogue about ways to approach such distress, e.g. Schwartz rounds (staff forums for reflection on ethical issues – not case review).
<https://monashhealth.org/schwartz-rounds/>
- Referral to a clinical ethics service for consultation, advice and support.
- Policy/guidelines that attempt to breakdown long-standing institutional cultural barriers that preclude nurses (and other less “powerful” health professionals) from being centrally involved in end-of-life care treatment decisions.

As Reed and Rishel put it in summing up their paper:

“Frontline nurses are pivotal in end-of-life patient care. A goal would be to initiate and establish guidelines that inspire more inclusive interprofessional practices in end-of-life patient care contexts; these practices would not only enhance wise and timely decisions about patient care and treatment approaches, but may also diminish nurse moral distress and the abundance of problems associated with moral distress.” (3)

References:

1. Jameton A. *Nursing Practice: The Ethical Issues*. Englewood Cliffs, NJ: Prentice-Hall; 1984.
2. Peter E, Liaschenko J. 2013. Moral Distress Reexamined: A Feminist Interpretation of Nurses’ Identities, Relationships, and Responsibilities. *Bioethical Inquiry* 10:337-345.
3. Reed PG, Rishel CJ. 2015. Epistemic Injustice and Nurse Moral Distress: Perspective for Policy Development. *Nursing Science Quarterly* 28(3):241-244.

Dr Greg Mewett

Palliative Care Physician
Grampians Regional Palliative Care Team

CONTACTS

Grampians Regional Palliative Care Team Ph 5320 3553
Central Grampians Palliative Care Ph 5352 9465
Gandarra Palliative Care Unit Ph 5320 3895
Grampians Region Palliative Care Consortium 0428 737 330

Ballarat Hospice Care Inc Ph 5333 1118
Djerriwarrh Palliative Care Ph 5367 9137
Wimmera Palliative Care Ph 5381 9363

JAN/FEB 2020



www.grpct.com.au

