OPINION

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Can we do less but care – fully?

Moral distress is a key challenge in the South African healthcare environment. It has arisen from a combination of declining healthcare resources, a crumbling infrastructure, an increase in the burden of disease, enduring healthcare inequalities, and the additional burdens of violence and substance use in our population. The frequent absence of adequate medical ethics training and a healthcare culture that does not promote acknowledging uncertainty or display of emotions or vulnerability add to the risk of experiencing moral distress.[1]

Given this context, it is unlikely that we can banish this experience entirely for our healthcare workers. Exploring better ways to support them through the distress experienced when it does arise is critical, given the role of moral distress in burnout and depression in healthcare workers. Lewis[2] has suggested that designing an environment aimed at encouraging moral decision-making and empowering decision-makers to act is one way to address moral distress. Khaghanizadeh *et al*.[3] have reported that training in ethical decision-making through lectures and group discussions had positive effects on moral reasoning, moral distress and moral sensitivity in nurses. Schafer and Vieira[4] argue that ethics education is essential to help healthcare providers cope with the ethically distressing burdens of their work.

The idea that ethics education can offer a way to counter moral distress led to the establishment of a monthly Clinical Ethics Forum (CEF), hosted by the EthicsLab in the Faculty of Health Sciences at the University of Cape Town. The aim of these meetings is to offer clinicians the opportunity to explore the *moral* component of distressing clinical situations or encounters and to provide them with the tools to address these. The CEFs bring together varied healthcare professionals and others, including for instance moral philosophers, bioethicists, psychiatrists, palliative care clinicians, and other professionals across the field of medical and surgical disciplines, including medical management. At each CEF, a clinician or clinical team presents a clinical case study that they found distressing, after which attendees are invited to explore the case from different practical, clinical and ethical angles. The multiple lenses brought to the sessions through individuals' diverse training and experience facilitate the development of logical reasoning and critical thinking skills to promote productive ways of dealing with the ethical complexities that characterise healthcare settings. The aim is not primarily to come up with solutions, but rather to curate a space where clinicians are encouraged to recognise moral distress and acknowledge that it is very real, often unavoidable, and above all, not shameful.

A recurring ethical challenge that has emerged in cases brought to the CEF relates to the ethics of withholding and/or withdrawing treatment. Specifically, clinicians frequently grapple with questions of whether, at what point and for what reasons it is ever appropriate to stop treatment that has been started – or to not start treatment in the first place. Related to this is the question of what level of treatment is 'enough' – and whether we can ethically consider the opportunity costs of treatment that is offered. To highlight these dilemmas, in this article we discuss two cases, both involving patients admitted to a tertiary care academic hospital.

The first case involved a 40-year-old man with a history of living with HIV who had, for unknown reasons, discontinued antiretroviral therapy. He presented with a chronic productive cough lasting over 2 weeks, accompanied by significant haemoptysis and weight loss. On admission, his CD4 count was critically low at 3 cells/µL. His prognosis was assessed as poor, largely in view of profound immunosuppression, the development of progressive multifocal leukoencephalopathy (PML), and several additional opportunistic infections leading to further deterioration. In keeping with PML, he developed neurological symptoms, including ataxia, blurred vision, and left-sided weakness. As his clinical condition continued to decline, a decision was made to transition to palliative care. At this point, the question of whether to continue antibiotic therapy was raised, with the ethical dilemmas of beneficence, non-maleficence and justice explored. Was further treatment going to benefit the patient? Would withdrawing antibiotic therapy cause harm? Given the very high cost of the antibiotic therapy, was continuing with it a prudent use of resources? Ultimately, the decision was taken to continue antibiotics but discharge the patient into the care of his family to receive palliative support at home, where he died shortly thereafter.

The second case involved a 65-year-old man with diabetes. He was blind, and had suffered a stroke in 2022 which resulted in a dense right hemiplegia and expressive aphasia. Since then, he had been bedridden, cared for by his wife and son at home, but able to feed himself and communicate with sign language. He was admitted to hospital after 4 days of confusion, vomiting and not eating. On admission he was dehydrated and obtunded, with widespread contractures. Clinicians were initially unable to contact his family. He was initiated on antibiotics for urosepsis and given intravenous fluids and nasogastric tube feeds, but after 72 hours there was no improvement in his mental state. He stayed in hospital for 18 days and had new imaging (computed tomography of the brain) and multiple blood tests, until his family was finally contacted and joined a multidisciplinary team discussion. He was discharged home and died 2 days later.

The clinicians presenting their cases were clearly in anguish and repeatedly questioned whether they were doing (or had done) the best thing for their patients, their patients' families, and society at large. Specifically, questions arose about whether clinicians should provide maximum care despite the multidisciplinary teams' clinical assessment that the addition of these treatments would not improve the overall prognosis for the patient in their care. Or, if it is reasonable for them to withdraw or withhold treatment that is unlikely to lead to a real improvement in the patient's health, whether in making that decision they should consider the overall cost of treating that one patient to the hospital overall, particularly when considering costly interventions. With every drug prescribed, there is less to give to subsequent patients. What is the best thing to do in such cases?

The ability to see the whole picture with all its intersecting pieces is key: particularly where one element of the case is potentially reversible – by refeeding, rehydration, or treating pneumonia, for example – but still highly unlikely to change the overall outcome, which is that the

patient is critically ill and dying. A patient's multiple complications are not siloed, but all contribute to the overall prognosis. Determining exactly how each interacting condition worsens prognosis is difficult, and sometimes different for each patient. So we are left sitting in the 'grey', having to make the best decision we can with the current available evidence. In the first case described, for example, would the addition of more antibiotics to treatment already given be able to reverse the trajectory of all of the complications of advanced HIV? If we add this antibiotic, what is the best outcome we can hope for in the patient we are treating?

In both CEFs, there was almost complete unanimity that there was 'too much' active intervention and 'not enough' of a shift in approach to palliative care. Importantly, we need to be able to acknowledge that while a decision may be made to withdraw treatment, we never withdraw care. The clinicians explicitly questioned the approach of 'prolonging life at all costs'. They all indicated their conviction that maintaining dignity during end of life, improving the quality of remaining life, and supporting family members during this difficult period needed to be the focus. One clinician expressed her concern that the job of taking instructions from the family is often left to junior doctors who, unsurprisingly, almost always receive an affirmative response to the question 'Would you like us to do everything possible?' In response, it was suggested that the focus of discussions with families should arguably move from that question to another: 'What are you hoping for?' Shifting the discussion with family in this way would allow the treating team to understand family expectations, and to develop an action plan appropriate to these. Such a plan may require resetting hopes and expectations and recognising that in such instances the 'best treatment' may not depend on evidence, but on respecting the patient's values, sense of dignity and understanding of quality of life.

With regard to the key ethical question of justice, similar concerns were raised: when is it 'just' to stop treatment, and when is it 'just' not to start treatment? One suggestion was that treatment to ease suffering is the ethical requirement and should be the focus of end-of-life care. In the first case, justice may suggest that in a setting of limited resources, treating multidrug-resistant pathogens requires prudent use of restricted, costly antimicrobials. Limited antibiotics might need to be allocated to individuals with a good prognosis for recovery rather than to those for whom the addition of the antibiotic is unlikely to change the trajectory of the poor prognosis. There is an obligation – ethical as well as clinical – to preserve antibiotic sensitivity in the population, especially given the estimate that by 2050, 40 million people will die every year due to antimicrobial-resistant organisms.[5] At the same time, if antibiotic treatment can reduce the symptoms of inflammation and increase patient comfort, even in palliative care, then perhaps the ethical imperative to treat can outweigh the public interest.

What emerged through discussion is that a decision whether to treat or not needs not to be seen as a once-off decision. Every next dose of a medicine or next treatment offers new opportunities to re-evaluate treatment options. Factors thought of as reversible at time 1 might not be considered as such at times 2, or 3, or 5. Continuing with treatment in the face of evidence that it is 'not working' might in itself be unethical, at least in terms of justice and care. In this regard, a palliative care specialist extended the insight that 'any decision is action' – so even the decision not to continue with a particular treatment (or not to start it in the first place) was not neutral, and required honesty and courage.

What the contribution signalled was a reflection of the ethical virtues that healthcare providers need to cultivate. Ethics in healthcare is not just the four principles that help us decide what is the right thing to do. Virtues such as honesty and courage help us be the right kind of practitioners. In virtue ethics terms, these are practitioners who are able to make the best decisions at the right time with the information available, while at the same time acknowledging that there may be gaps in what we know. In addition, we need to work on being comfortable sitting in the grey space where the answer is not clear. Moral distress is often unavoidable; providing clinicians with opportunities to talk about and reflect on the causes of moral distress can, we think, help mitigate the negative consequences of moral distress such as loneliness, depression and burnout.

The virtue of honesty requires having difficult conversations with patients and their families. These conversations include being able to answer truthfully the question 'What is the best we can hope for by adding this intervention/treatment?' The virtue of courage allows us to make the tough decisions when it comes to withdrawing or withholding treatment, while we continue to provide care. Neither of these virtues supports terminating care. Being honest or courageous enough to terminate treatment is, for many, the ultimate example of care. Of course, families (and patients themselves) may need additional time to process what is happening, and providing treatment during this time can offer this. However, honesty and courage necessitate explaining that giving them this time is the point of treatment – rather than meeting their (often) unrealistic expectations of what such treatment can do.

In this way, we offer full care – even when doing less.

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S Afr J Bioethics Law 2025;18(3):e3886. https://doi.org/10.7196/SAJBL.2025.v18i3.3886

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