

“Ignorance is bliss?”: With attention to ethical theories, discuss the role of truth-telling within good palliative care?

My defining memory of my trip to Uganda is an enraged and desperately ill woman, trying to walk on grossly swollen legs, waving her fists and clearly communicating that I was not welcome. Her shouting turned to coughing and gagging as mucus clogged her mouth. I desperately wanted to do something, but with horror realised I did not have anything to offer. I was shocked, as after many years in eastern Africa I had never felt unwelcome. I wanted to hide behind the American family doctor I was paired with and let him, somehow, sort it out.

I arrived in that woman’s garden in January 2018, invited to join a group of physicians, nurses, and healthcare students from all over the world to study social medicine and advocate for global health equity, focusing on the social determinants of health. We were brought to a rural clinic and sent to meet the community. I was paired with that American physician, soft-spoken and intensely competent. Suffice to say that I was deeply grateful for his presence. The details were murky, but we were told that a group of doctors “from the west” had visited months before, and one of the doctors told this woman that she was dying of heart failure. She seemed to understand that there existed some treatment for the condition, which was too expensive and not available nearby. Her takeaway from meeting that doctor was that she would die, but had she been wealthy or not Ugandan or lived somewhere else, she would be cured. Unsurprisingly, she had no interest in seeing a foreign physician ever again.

Now, as I approach my final year of medical school, I understand the basic pathology of the condition, of the ways her heart and lungs and vessels were under deadly pressure. A cardiologist I am not, but if I am now asked a few basic questions I could likely provide a passable overview of the Four Pillars of Heart Failure, perhaps explain the likely course of the disease or name a few complications. All of this would, of course, have been entirely

unhelpful to this woman. What she needed was a system that could care for, treat, and support her. At that moment, she needed palliative care.

Doubtless the argument could be made that it would have been more humane, more ethical, to not have told her the diagnosis. In fact, when I have discussed this experience with others, they often gasp indignantly at the audacity of a western physician to appear in rural Uganda, bestow diagnoses, and leave without offering treatment. I do not disagree; I think his behaviour was abhorrent. The conversation typically falls back on the foundational ethical principles we learn in medical school. Like generations before, the first framework I learned was Beauchamp and Childress' four principles, which over the past forty years has continued to be a bedrock in our attempt to make ethical decision-making in medicine. The most famous of these principles is likely non-maleficence, known worldwide in its Latin form as "primum non nocere" and in English as, "first do no harm."<sup>1</sup> The physician who had told that Ugandan woman of her disease had quite clearly violated this principle. The principle of non-maleficence does not specify that the harm be physical, and in this case it was clear that the woman's emotional health was severely impacted by what he had told her. Further, Beauchamp and Childress were clear that this pillar holds whether negligent or purposeful. Regardless of the physician's intentions, he had caused harm.<sup>1</sup> This situation also calls into attention another principle, beneficence, which mandates that all of our actions should be in the best interest of our patients.<sup>1</sup> It remains a mystery to me as to what benefit he could foresee by telling the patient she would die but offering no treatment or comfort. When I have told this story, the discussion ends here.

I feel an uneasy sense that we are missing something when we end our discussion at this point. Whether or not this woman knew the name of the disease, she was living its deadly effects. She did not need a physician to tell her that her heart was not working, that her breathing was belaboured, that her limbs were swelling and she felt bone-deep fatigue. Her

entire family was bearing the consequences of her disease, as she could not care for them. No one needed a doctor to confirm it was catastrophic. However, according to Beauchamp and Childress, she did in fact deserve to know her diagnosis. In order for the patient to have full autonomy, another pillar, she must be provided honest and accurate information to make her diagnosis. She cannot be manipulated, coerced, or persuaded to make choices.<sup>1</sup> The role of the physician is to give her the best information and respect the decision she makes, and in fact studies have shown that patients want the ability to make fully informed decisions.<sup>2</sup> I am left wondering how I would have reconciled my dual mandates to tell the truth and cause no harm in a situation where treatment was unavailable.

I am forced to conclude that ignorance is bliss, but not for the patients; it is bliss for us, the student doctors and physicians. Perhaps our discomfort with what happened in Uganda is knowing that the woman's "ignorance" would have spared us from having these conversations. Ignorance would allow us not to question our role in some people having access to a cardiologist, while others will never see one. We do not have to feel a bubbling panic at the thought that we too could have been born in a place where we might not have access to a doctor. We would not need to ask if we personally have any responsibility in the face of global health inequality. Beauchamp and Childress' final principle - justice - may be the one we want to believe in most, but is the most difficult to fulfil.<sup>1</sup> We may believe in it, that everyone should receive the care they require. We do not know how to ensure that will become reality, and in situations such as the one in Uganda, we must reckon with that unknowing.

We perhaps feel discomfort knowing that "ignorance" removes the burden of heartbreaking conversations with our patients and their families. We could say we have "done everything we can" and let others bear the grief. We feel discomfort with this story because we could so easily be that physician - busy on wards, giving a difficult diagnosis and then

rushing to the next task, silently hoping our patient will not have questions or will find someone else to ask. We have all been taught, in accordance with WHO literature, that dying is not a medical procedure. We are taught to neither hasten nor postpone death, but to support our patients and their families as they move through the process of dying. We are told to work within a palliative care team to ensure our patients are medically, psychologically and spiritually cared for.<sup>3</sup> The Guide to Professional Conduct and Ethics for Registered Medical Practitioners is very clear - communication with patients and their families is “an essential part of good care” at the end of life.<sup>4</sup> I believe we believe all of these things. Yet, it does not come naturally. We worry we will be asked questions that we cannot answer, because of inexperience or ignorance or simply because there isn't an answer, and will have to admit our failing to desperate patients. We may be asked to organise support for patients and families, adding work to our brutal workloads. We are uncomfortable that our idealism and our promises that we will never become “that doctor” are eroded under the pressures of the systems in which we work, our responsibilities to our own families, and our own needs. And so we hope for ignorance, to relieve our own discomforts and insecurities with death.

During my first degree, the head of my Humanitarian Studies programme, Dr Alexander van Tulleken, repeated relentlessly, "Good intentions are not enough." He is a former humanitarian physician, and I often felt frustrated during my undergraduate degree - I wanted him to teach me rare diseases, show me photos of the maimed he had treated, tell me about the world's suffering and how to cure it, give me the tools to rebuild refugee camps and cure the world. I did not want him to tell me that my good intentions were not only insufficient, but they could harm vulnerable people. Instead, he painstakingly taught me those things that might actually change someone's life - an ability to see a patient in front of their disease, rather than the other way round; how people are defined by their music and food and poetry, not the diseases that afflict them; that our desire to heal is second to the desires of

those in need of our skill; the extraordinary privilege of being invited to bear witness to someone's pain.

Those things that Dr. van Tulleken spent years teaching me are the difficult parts of medicine, particularly in palliative care, and require the greatest time and commitment from physicians. As the Irish Hospice Foundation states, “We only have one chance to get it right.”<sup>5</sup> We can choose ignorance, or we can choose to embrace the honour of being welcome into patients’ lives in these most difficult moments. We can dig deep and have the most heartrending conversations, and we can work to ensure our patients’ desires are met. Beauchamp and Childress’ principles seem also simple in comparison to what the end of someone’s life requires of physicians - disconnection from the biomedical model, reconnection with ourselves, and to simply accompany. This requires us to have an intimate and deep understanding of ourselves, how we think about our own mortality, and the most important aspects of our lives. Most importantly, it requires us to have the confidence to deal with the privilege and pressures that being invited into the ends of our patients’ lives brings.

A 2000 study, “In search of a good death: observations of patients, families, and providers,” found that patients and their families viewed their psychological and spiritual health as important as physical health at the end of life. The physicians in the study had a different perspective rooted in the biomedical model. Yet, “Participants identified six major components of a good death: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person... each has biomedical, psychological, social, and spiritual components.”<sup>2</sup> Regardless of the perspectives with which we approach palliative care, there are foundational aspects we can agree upon. The Declaration of Geneva, with its most striking first line - “I solemnly pledge to dedicate my life to the service of humanity,” has changed very little since 1948. I suspect this is because the things that matter most to our patients - our empathy, our time, our

connection - have not changed, even as medicine has.

When I read the prompt for this assignment, I immediately thought of that January afternoon in Uganda. After five years of study, I still would have no cure. I hope, however, that if I had the opportunity to meet her again, I would not shy away from the humanity connecting us across the 7000 kilometres between Uganda and Ireland; that I would fight for her dignity in death; that I would allow my heart to break as it beared witness to the crushing inequality allowing her suffering. Dr. Paul Kalanithi wrote, “The physician’s duty is not to stave off death or return patients to their old lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence.”<sup>6</sup> I hope that now, I would not turn away, but I would take her into my arms.

## References

- <sup>1</sup>Beauchamp TL, Childress JF. Principles of Biomedical Ethics. 8th ed. New York: Oxford University Press; 2019.
- <sup>2</sup>Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine*. 2000May16;132(10):825–32.
- <sup>3</sup>Power J. Palliative Medicine - Clinical challenges in care of the dying person. Lecture presented at University College Dublin School of Medicine; 2022 Mar.
- <sup>4</sup>Medical Council. 8th ed. Guide to Professional Conduct and Ethics for Registered Medical Practitioners (Amended) Dublin: Comhairle na nDochtúirí Leighis; 2019 p. 1–48.
- <sup>5</sup>Toolkit for Compassionate End-of-Life Care Dublin: Irish Hospice Foundation; 2021 p. 1–41.
- <sup>6</sup>Kalanithi P. When breath becomes air: A memoir. New York: Random House; 2016.