

1. Pulling the heartstrings, arguing the case: a narrative response to the issue of moral agency in moral distress.
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3. Key words: narrative, moral distress, moral agency, emotion, conscientious objection.
4. Word count: 3 520.

Abstract

In this paper it is argued that moral distress is an emotional response to an ethical dilemma, and that to date the literature has largely failed to address the fundamental questions that need to be answered in response to this emotional response. Firstly does moral distress accurately identify a wrong being done to patients? Secondly, if it does, can nurses carry out this 'wrong doing' but not be responsible for the consequences of their actions? A narrative that reflects the emotional nature of moral distress is presented, with the aim of providing some answers to these questions.

Introduction

There is a pervasive premise in medical ethics following a long tradition in philosophy: that is, that a dichotomy exists between the emotional and rational self, and that ultimately it is the rational self that ought to be relied upon for ethical decisions. However, the emotions can be seen to play a motivating role in ethical living.[1,2,3] Their inclusion in the concept of self, and arguably the professional self, can be seen to be central to a sense of unified agency.[4]

Supporting this stance, much of what is experienced as 'ethical' in the clinical environment presents itself primarily in an emotional form. At its most raw this emotion can be described as 'distress'. One such form of distress is termed 'moral distress'. This has been described as the feelings and experiences which result from a moral conflict, where one knows the correct action to take but constraints lead to an inability to implement this action.[5] Moral distress is often experienced in relation to medical care that is perceived by nurses to be futile and that they feel complicit in contributing to. This will be the focus for this paper.

Solutions to moral distress have been offered, such as promoting multidisciplinary collaboration through ethics training and ethics rounds. The only available study to address the effectiveness of such interventions in relation to moral distress in nurses, found that although staff valued the interventions, they had no impact on the degree of moral distress that the staff experienced.[6]

I propose that a significant cause for this is that such interventions tend to rely

on principled ethical analysis of patient care decisions. In so doing, they overlook the emotional experience of 'moral distress' that I will argue, is directly related to the nurse's sense of moral agency.

In this paper, I will present an experience of moral distress in narrative form. I will argue that in such a situation the emotional response leads two fundamental questions for the nurse to answer. Firstly, she needs to identify whether or not the act in question is objectively wrong for the patient. If the answer to the first is yes, then secondly, she needs to address her moral agency in relation to the act. She needs to decide whether or not it is wrong for *her* to carry out that act. Conscientious objection is one action she could choose to enact and has already been proposed as a valid solution by Kalvemark et al, who argued that nurses working in neonatal intensive care should be supported to conscientiously object to involvement in medical care that they perceived to be futile. If instead, she decides to carry out the act, she has to decide whether or not she is correct in her perception of moral agency; that is, that in carrying out the 'wrong' act, she is indeed responsible for its consequences, and therefore suffer moral distress. The alternative to this is to accept that even if the action is wrong for the patient, the nurse is not wrong in performing the act, because it has been prescribed by someone else. The latter decision will not remove all distress, but it will remove 'moral distress', that has been described, and perhaps under most circumstances, is wrongly identified as a valid perception of wrong doing.[7]

In keeping with the emotional nature of moral distress I will now present the narrative that remains grounded in the nature of the experience, and that also

attempts to offer arguments in support of one set of answers in relation to the questions above.

Grim orders and fragile birds.

It is the year 2000 and I want you to imagine a ward of patients. You are in a nurse's uniform. You are young and junior. Your name badge announces you as 'Staff Nurse'. There are bays along the length of the ward, each housing eight patients, most with small machines by their beds that will spew clouds of medicine via facemasks. Just now the machines are quiet. But wait until the drugs round, and one by one they'll waken, the sound of clapped out motors reaching a crescendo, until one by one the patients turn them off. The ward is full. Patients sit. Some wander. Others lie in side rooms with half closed doors. In one of the bays, sitting in the corner is an old lady. Her hair is curly grey. The nightdress she wears gapes about her chest. Its shoulders appear to hang off a coat hanger. The sleeves are billowy with skinny arms flapping between. The fabric that used to fit now serves as a frame that draws attention to the skeletal body that the woman has come to inhabit. The flesh on her face has collapsed into the shape of a skull. Her dentures rattle and dance when she speaks. Her eyes are bright blue. They shine and dart side to side until you approach, sit, and touch her to gain her attention. There's something bird like about her. Let's call her Mrs Bird.

Her eyes settle and rest into yours. The tubing snaking from the wall, across her bare ribs, around her ears and nose delivers oxygen. No, breathing isn't quite the right word. Panting. She pants, and has done for years.

You touch her hand. Her fingers are cold, her lips have a blue hue. The oxygen helps to keep her alive. Alive enough to eat tiny portions of food. Alive enough to have an echo of recognition when she sees her son visit. Alive enough to have a sense that there are things to do. Alive enough to feel the oxygen tubing pulling at her face when she gets up to see to her jobs. Alive enough to have the sense - in the midst of her confusion - to take the tubing off and wander in pursuit of what exists in her thoughts. Alive enough to feel your hand and to be comforted by it.

The doctors do their round and take note that you have seen her condition deteriorate. This is her third admission in two months. Her stiffened lungs are not responding to the antibiotics and steroids that will clear infection and reduce inflammation.

At the end of the round the charge nurse approaches. He tells you that Mrs Bird is to have a doxapram infusion. You feel your chest tighten. It's a drug that makes patients breathe harder. It makes their muscles tremble. They don't sleep. They are agitated. The last gravely ill person you managed on this drug reminded you of a hunted fox. You nursed him through the night, his sweat marking your shoulders with its stench as you moved him up and down the bed, trying to make him comfortable, the drug and its stimulus to breathe combating you in your

efforts. He died a few days later. What about her steroids? Are they increasing the dose? Are they going to change her antibiotics? No, just doxapram.

You begin to argue. What is the point of giving doxapram without treating any underlying condition? She wouldn't be ventilated so why make her self ventilate? With no hope of alleviating underlying conditions she will self ventilate and most likely die on the drug.

Your primary nurse arrives. The sentence 'we don't commit euthanasia' is spoken. Next is the junior doctor. You explain what is wrong. He takes you to the desk and draws a picture to show you how doxapram works on breathing rate and depth. You have a sudden flash of anger and feel like slapping him. You've worked in intensive care and so you slap him with this information instead. He apologises. Still no one 'gets' it until the registrar arrives. You speak to him. He listens. He says he thinks you're perfectly right. There is a moment of relief; at least you have been heard. But he continues, that the consultant is now gone and the team will follow his plan. Then comes desperation; nothing will change. You are not the person who can alter the course of medical treatment. You have argued your case. You have taken it to the highest level. You have been understood. But the senior doctor makes the decision.

So stop. Take in what has happened so far. Touch the smooth steel of the artery forceps in your breast pocket. You have spent the morning helping patients to wash and to clamber to the commode. The Irish patient has joked with his fellow inmates that you are 'the flasher', you having woken him a few nights ago with

your torch shining in his face to make sure that he wasn't dead. He wasn't dead, but the shock of waking to the bright light and you looming anxiously over almost killed him. You have travelled to and from the sluice to dispose of urine and faeces and then pushed the drugs trolley from bed to bed. You have informed relatives of a patient's death and laid out the body ready for their arrival. Next door another patient is dying. You have cleaned his mouth and turned him. As is the case with every early shift, you sweat. Mrs Bird is looking out of the window, the fan that helps her feel more able to breathe, blowing a breeze into her face.

The charge nurse sees that you are visibly distressed. Academics would state 'morally distressed.' It's the distress you feel because you believe you know the right action to take, but are not able to carry it out. He touches your arm – you will not forget his compassion. He tells you he can see how upset you are, that it is ok and he offers to put up the infusion for you. You have been offered the opportunity to conscientiously object to carrying out a medical treatment.

Let the ward lights dim. Let the scene fade to darkness. Let yourself take centre stage. Let the spotlight shine on you. It is time to examine your conscience. You have been asked to perform an action. You believe that the action is wrong. Most likely it is wrong. You have the opportunity to remove yourself from that action. Your charge nurse will assemble the equipment, prepare the infusion and attach it to Mrs Bird. He will set the rate and press the start button. Your 'hands' will be clean. Such a simple answer to the situation. Your distress will ease. Your

autonomy and integrity will be protected. But is this the right thing to do? Ought you to be the focus? What about Mrs Bird? What about the other patients?

What does it mean to be their nurse and where does your responsibility lie? Most importantly where does your responsibility end? And when you define its limits – if you exchange some autonomy for some humility - does it free you of a burden in order to do something else?

The dying patient in the side room needs to be turned again. His mouth is dry. It is time to soak a sponge in water and then rest it in his mouth. He appears unconscious but will furiously suck when the sponge touches his tongue. Such matters are the responsibility of nurses. Tedious, repetitive and physically demanding labour that eases suffering and that literally protects patients' bodies from decay.

Your code of conduct does not allow you to conscientiously object to carrying out medical treatment, or dare I go as far as to say 'carry out a doctor's orders'? Academics tend to focus on your distress and your powerlessness. They wish to promote your professional autonomy. The solution is to alleviate it with empathic workshops, ethics rounds and egalitarian collaboration between health care teams. But this is a busy medical ward. Mrs Bird is getting up. She pulls at her nightdress. You need to make sure that she does not wet herself. That she sits down before she falls.

There is an error made in medical ethics when your moral distress and lack of autonomy becomes the focus of research and attention. There is more to this scene than meets the eye of many ethicists. You are a nurse. You can engage in what is seen to be lofty debate about the rightness of medical intervention and indeed I do not want to suggest that you ought not to have argued the case against doxapram. An opiate would have eased her. However, don't forget that the important person is Mrs. Bird. It is not you. Whilst you discuss and distress about whether or not she should have the drug, whether or not you put up the infusion or who else can do it if you don't, Mrs. Bird is thirsty. She has been sat too long and the skin on her buttocks will start to peel. She hasn't passed faeces for three days and is feeling bloated. Is thirst or constipation any less of a distressing symptom than side effects of a drug? Is it less deserving of attention?

Take yourself to the medicine room. Prepare the infusion. Accept that you now perform an action for which you can limit what you are responsible for. It is the doctor who has prescribed the medication. It is the doctor who has refused to alter the course of treatment despite his agreement with you that it is not the best treatment to proceed with. This is not murder, it is at worst a bad medical decision, but who knows what might happen next? The odds are that Mrs Bird will die, but remember you deal in odds and they are not a certainty. Accept that at worst Mrs. Bird will most likely suffer side effects that will distress her and that in a better world she would not be receiving this drug. Accept that in a better world she would not suffer respiratory failure. Accept that in this world you can only do your best under the circumstances. Limit what you are responsible for - you will be responsible for making sure that the drug is at the

correct dosage, that it will infuse correctly and safely and that you will watch her closely for the coming hours.

Know that you have an obligation to free yourself from the burden of the sense of responsibility that it is you who will cause her to suffer when you start the infusion. Know that in freeing yourself from this burden you will be free to do something else for your patient that will be equally or more emotionally demanding to you than the guilt, anger and dread that you currently experience. You will be free to feel compassion. You will be free to consider her needs rather than your own. You will be free to nurse her – that is to remain close rather than avoid her, to walk with her whatever path unfolds. This is the essence of nursing – to remain with the patient and walk with them every step of the way; to remain with the patient when all the other professionals walk out of the door. If you conscientiously object to her treatment, if you walk away, you will no longer be her nurse.

It is time to bring the medication to Mrs. Bird's bedside. You push the infusion pump to her bedside. You sit. You touch her hand. You explain that the doctors have decided to give her some medicine. You tell her that it will help with her breathing. You tell her that you will keep an eye on her. She looks into your eyes and for a little while looks peaceful. It is not long before you see the tremors start in her hands.

The act is done. You have made the decision to set up the infusion for your patient despite the charge nurse offering to do it for you. At the time you

believed that you ought to follow your code of conduct, and carry out your duty to follow prescribed medical treatment.

You went home that evening feeling defeated and with the emotional strain of having felt that you had done something in a caring manner that was wrong. You felt duplicitous. I wish, watching you ten years after the event, that your ethical reasoning had extended beyond your code of conduct duties and the sense of loss of integrity that resulted. If only you had had the humility to limit your sense of responsibility and in so doing that you had freed yourself to concentrate on nursing care. If only you hadn't have felt inclined to take flight from Mrs Bird, as the researchers have found happens, because all you could see was the wrong doing of the medical intervention and your own complicity in causing that harm.

If only you had also realized something else. That we are limited by the point of history with in which the stories of our lives are told. Today palliative care teams are involved with patients such as Mrs Bird. The limitations in her care were as much a reflection of the times in which she was sick, as a reflection on the characters who crossed her path during her hospital stay.

But the present tense does not have the benefit of hindsight. It is time to return to the year 2000. You are in nurse's uniform. Your name badge announces you as 'staff nurse'. You arrive in the ward the next morning. At handover you ask how Mrs Bird has fared overnight. You are told that she died in the early hours with the doxapram infusion running. You know she had struggled for last hours of her life. There had been no palliation of her symptoms. Although her death was more

difficult than it need to have been, she had been warm, she had not been thirsty and she had been cared for. As the dawn begins to break the junior doctor, who was on call all night, discusses the coming ward round with the charge nurse. The registrar is at home rising from his bed. The patients begin to switch on the machines by their beds, the sound of clapped out motors rising and filling the air. You are sad, weary and carry a burden of guilt but it is time to go and lay out Mrs Bird's body in readiness to greet her son. He will be coming to pay his last respects soon.

Conclusion

I hope that this narrative has conveyed the emotional nature of moral distress as it is experienced by the nurse. This distress is perhaps uniquely difficult for nurses. They have an intimate knowledge of the patient. They have an intimate knowledge of the benefits and harms of medicine, and are intimately involved in the suffering that results both from disease, and from the practice of medicine. Despite this intimate knowledge, they are not in a position to make final decisions about what medical treatment will or will not be carried out.

This narrative raises some of the issues that are not addressed by most of the current literature. In this narrative I have argued that nurses, once they have advocated for their patient, can absolve themselves of responsibility and carry out medical procedures without carrying responsibility for their outcome. I have argued that the prime responsibility of the nurse is to nurse her patient and that in doing so, she is free to express compassion, the emotion that is in itself

distressing,[8] but that motivates her actions in satisfying the most basic of her patient's needs. Such detachment from a sense of responsibility for some actions that the nurse may perform will no doubt have serious contenders.

I have shown that the experience of 'moral distress' most likely includes a variety of emotions, many of which are related to the incident in question but that are not moral in nature. Solomon has warned that although emotions can be accepted as moral judgements, it is important to correctly identify the object that they judge.[9] In this narrative, some of what could be identified as 'moral distress' was instead a sense of dread and foreboding for Mrs Bird, based on memories of having cared for a patient on the same drug. Some distress was anger at the uncaring and dismissive attitude of the registrar. I suspect that much of the distress experienced in 'moral distress' is an accumulation of such emotions and not specifically 'moral' in nature.

The potential for misidentification of moral judgments that arise from emotional reactions has meant that the most important question. That is, 'what exactly is 'moral distress'?' has not been answered by the literature, although many resolutions to it have already been proposed. Is it a valid emotional judgment of right and wrong that stands up to reasoned analysis? And if so, then that right and wrong has to be more explicitly identified. Is it a correct identification of wrong being done to patients, and if so, how are we going to put this right? Alternatively, is it a misidentification of wrong doing in the sense of individual agency, and that results in an erroneous sense of guilt on the part of the nurse? This narrative demonstrates that perhaps both are correct. In my narrative the

nurse was wrong to feel morally distressed for actions that were the responsibility of someone else. But the medical decision to treat the patient aggressively rather than palliatively, was also wrong, at least with the benefit of hindsight, which of course, as Dickenson [10] points out in her discussions of moral luck, offers a certainty that is not accessible in the present moment.

Acknowledgements.

Thanks to Dr. Angus Dawson for feedback on the paper and to the Summer Bioethics Internship at Yale University that lent wings to the ideas written in it.

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Competing interests

There are no competing interests for me to declare in relation to this paper

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