COPING WITH MORAL DISTRESS

A Guide for Healthcare Providers Caring for Patients with Serious Illness

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"...we have the gift and curse of extreme empathy and we suffer. We feel the feelings of our clients. We experience their fears. We dream their dreams. Eventually, we lose a certain spark of optimism, humor and hope. We tire. We aren't sick, but we aren't ourselves." [3]

– C. Figley, 1995

Introduction

Healthcare is delivered in environments dependent on decision making and therefore naturally charged with a potential for differences in value. In the course of caring for patients who are seriously ill, this environment becomes even more charged.[6]

Healthcare providers invariably see patients and their families more often as disease progresses. Longer and more frequent hospital stays involve more time, communication, and treatment choices. Inevitably more of the decisions made by providers and patients stand a greater chance of not aligning. A much broader range of personal values comes into play as the ethical questions inherent in shifting treatment goals increase and outcomes become less distinct.[4]

When personal values and morals are challenged during times of difficult decision making, moral distress is likely to occur. It can result when the prevailing sentiments of an encounter lead to these types of personal questions: What is the right action to take? Who am I as a moral person if I choose one way over another? What do I do if I am being ordered to do something I consider will cause more harm than good?

Moral distress has been defined as a sense or feeling that can arise when a healthcare provider knows what should be done in a morally charged situation but cannot or is not allowed to act on their choice.[1,8] It arises amid the complexity of value-based decisions that must be made during the normal course of providing healthcare. It can also impact a provider's well-being and ability to be effective in their work.

When experienced, moral distress often defies an exact rationale or immediate response, but if not addressed can lead to negative outcomes, including impacts on personal health and provision of care. The term has been in use for over three decades[8] and consequently various disciplines have worked to manage it through identification and the creation of various coping strategies for those who experience it.

Every healthcare provider has a personal moral code, a set of values that works in conjunction with their professional duty to provide beneficial and potentially curative treatment, to do no harm, and ultimately always provide the best care. Patients and their families enter the healthcare environment with their own respective sets of values. Among the myriad of decisions that must be made between the providers, and provider-patient interactions, it is inevitable that there will be differences in determining right and wrong actions.

This eBook is aimed at improving your ability to handle morally challenging situations in the workplace and where they spill over into daily life. It is intended to support a goal of strengthened professional and personal resilience to moral distress so the important work of providing all levels of care can continue.

This eBook will help you:

- Recognize moral distress in yourself and others by examining the relationship between personal values and professional ethics
- Understand moral distress, unpack its emotional influence and weight, particularly in end-of-life situations
- Respond to moral distress with personal and professional strategies. Additionally, this eBook will offer tools and strategies to cope with the challenges of future cases.

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Confronting a Patient's Autonomy: Helplessness, Preventable Harm, or Respect?

> *Visualize yourself in a patient's hospital room near the foot of the bed; a sickly odor is present despite the sound of the air-conditioner. There are no machines making noises but there is an IV stand. A family member stands on each side of the bed, one speaking in Spanish to her mother, the second speaking in English to you. He is pleading that you help them convince their mother to have surgery and stay alive.*
>
> *The patient is on her third day in the hospital being treated for advanced diabetes and a septic foot wound, including necrotic toe tissue. She is visibly in pain, anxiously and agitatedly stating in Spanish that she wants to go home.*
>
> *You have just been told that the patient is choosing to forego the physician's recommendation for amputation of her foot; she has stated she understands that the spread of infection will likely cause her death. She wants to go home.*
>
> *Imagine how this scenario would make you feel. Is it likely to leave you with a sense of moral distress?*

When moral distress occurs in the workplace it is usually because the healthcare provider knows the choice they believe ought to be made in a given situation, whether for the patient, by the patient, or by the family. In the provider's view, the proper action, or the morally sound, right action, would result in promoting good, would not cause harm, and would possibly prevent harm from being done.

Distress results when the provider is unable to or prevented from taking action on their choice. It is moral by description because the conflicted right or wrong choices inherent in the prevented (or imposed) action are rooted in ethical principles, or the reasoning behind what makes something right or wrong.

Moral distress can be rooted in a range of challenging issues routinely encountered in providing care and treatment to very seriously ill patients. These might include, but are not limited to:[2,4]

- Clarifying goals of care
- Defining quality of life
- Pain management
- Degrees of burdensome treatment
- Defining beneficial treatment
- Continuing with or ignoring ineffective and possibly futile treatment
- Withholding or withdrawing treatment
- Prolongation of dying
- Inadequate determination of levels of physical and non-physical suffering.

Returning to the story about the patient who wanted to go home, after visualizing yourself in the above patient's room, it would not be unreasonable for you to feel distress that she has a treatable condition but is declining treatment. Do you agree or not agree with her decision? Do you have to agree with her decision? What can you still do for the patient? Can you identify why this scenario might be distressful and why it is morally distressful? What can you do to alleviate your own sense of moral distress?

Learning to handle moral distress begins with recognizing it in yourself and others. Learning to identify the ethical issues in conflict is another technique. For example, it would not be unreasonable to find yourself asking, "Why does it seem wrong for the patient to go home and possibly to die of infection, a treatable condition?" What makes it wrong – that she might die or that she is refusing effective treatment? Conversely, what might make it right?

Step back and reflect on the fact that three sets of values are at stake: the patient's, her children's, and your own. But whose values, whose definition of right or wrong action ought to take precedent, be honored or rejected?

Here are a few more questions to consider:

- Can treatment be forced on this patient? Who determines what is "good" for her? Is her definition of "good" and "right" a value that is non-medical?
- If she does go home how do you handle your own feelings?
- What if the woman returns in a week to the ER in failing health because severe infection has set in?
- Are there limits to what medicine can or ought to do when it comes to respecting a person's choice, even it that choice might lead to their death?
- Are you feeling personally responsible in any way and what can you do with those sentiments?

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Common Categories of Moral Distress

Moral distress can involve more than a feeling or sense that something is wrong; it can reflect acknowledgment of missed opportunities to correct inaction or wrong, possibly harmful actions. It is valuable as a caregiver to be familiar with the most common sources of moral distress in the workplace. This awareness can help prepare you to learn to manage the distress and perhaps inspire you to take action and seek ways to affect the environment in you which you work. Studies focused on care of seriously ill patients on critical care floors and in palliative care found moral distress being experienced more frequently when dealing with these issues:[4]

- Quality of care provided
- Amount of care provided
- Inconsistent care plans
- End-of-life decision making
- Poor communication
- Interactions and conflicts between providers and family
- Recommendations for patient care ignored by other staff
- Lack of support or limited resources

The categories are broad because they cover an unpredictable and consistently changing range of human personalities, moral and ethical perspectives, and education gaps, compounded by varying cultural, theological, and ethnic perspectives. Ultimately, communication with others will be fundamental to relieving your own distress and possibly that experienced by the others involved in the case.[4]

It is important to remember first and foremost that you do not have to take on the burdens of moral distress alone. Communication with your peers, fellow healthcare professionals, the patient, and their family/surrogate decision-maker is essential and has been shown to be extremely helpful in the long run.[4]

Often the perspectives others hold have simply not been revealed or sought out.[6] Hidden within these perspectives are points of view and solutions to some of the most daunting dilemmas: the ones that set the burden of moral distress, persist as moral distress, and those that can lead to compassion fatigue.

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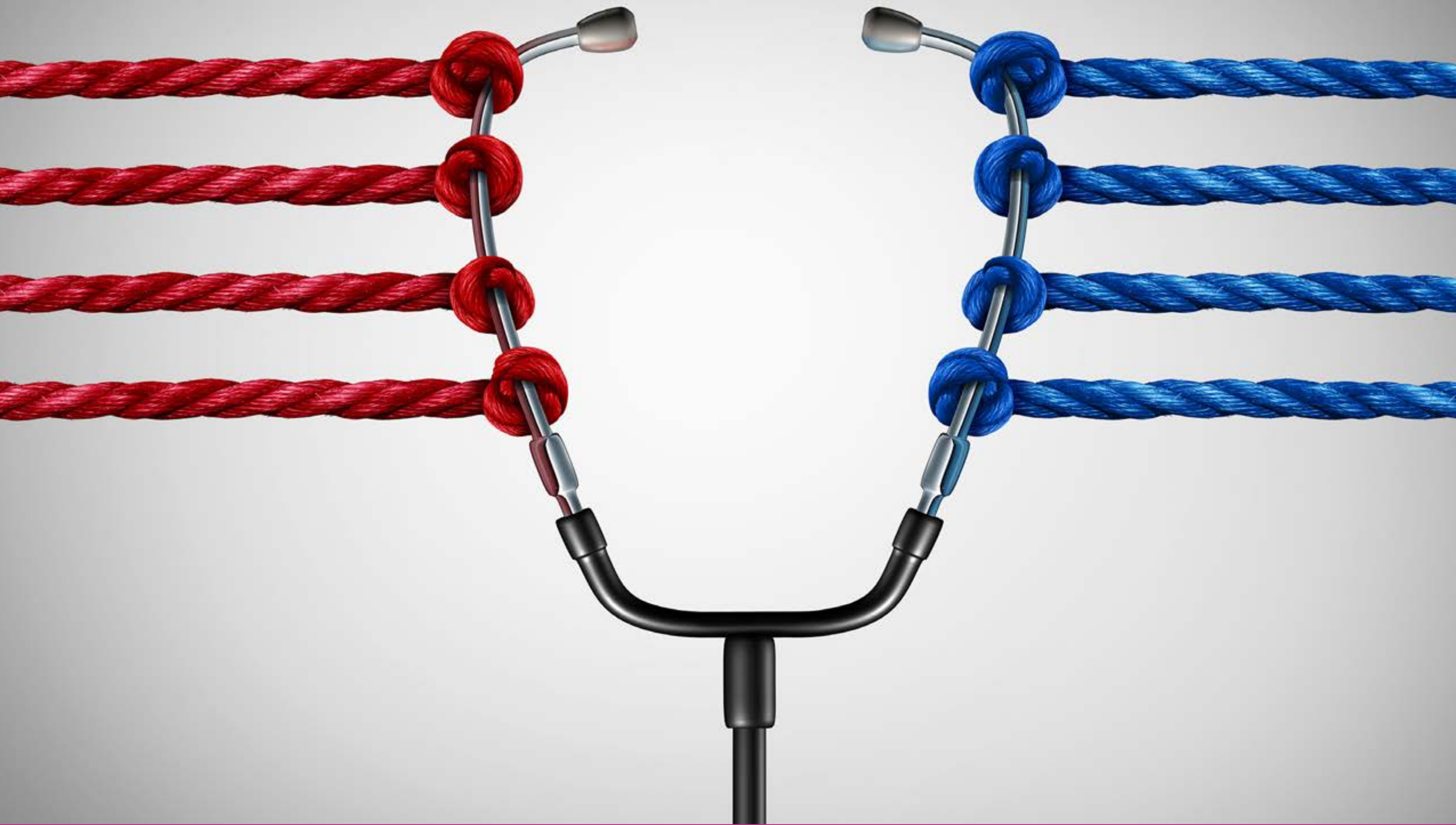


Moral Distress vs. Compassion Fatigue

Moral distress is different from compassion fatigue in that it is typically revealed during individual patient care experiences; its stress can be lingering but conflict and resolution (if applicable) are case specific. Compassion fatigue is a result of stress built up over time and through the course of multiple care experiences.[7]

Both moral distress and compassion fatigue involve personal emotions, professional opinions, and ethical perspectives on care and treatment of patients and their families and decision makers. People who choose to work in healthcare must act as independent thinkers in a constantly changing arena that demands a focus on the good of patients, essentially strangers in need. Every party involved retains their individual moral compasses; when these do not align with others, or when you as the healthcare provider feel you have no outlet for your opinion, and lose a sense of the control necessary to do your best work, distress occurs.[4]

Goals inherent to quality healthcare include preventing harm, providing safe and effective treatment, and maintaining a positive environment for all involved.[7] These goals are well met by people who naturally feel tremendous empathy and exhibit empathy. They respond to the needs of others and seek to provide relief.

For some providers, these efforts can leave lingering emotions and memories, especially about cases where their best efforts at preventing harm and providing safe, effective treatment are thwarted or minimized for reasons outside their control. Compassion fatigue may occur over time as the stress a person feels from the build-up of lingering emotions and memories is denied a relief outlet.[2,7]

The Impact of Moral Distress on the Ethical Delivery of Care

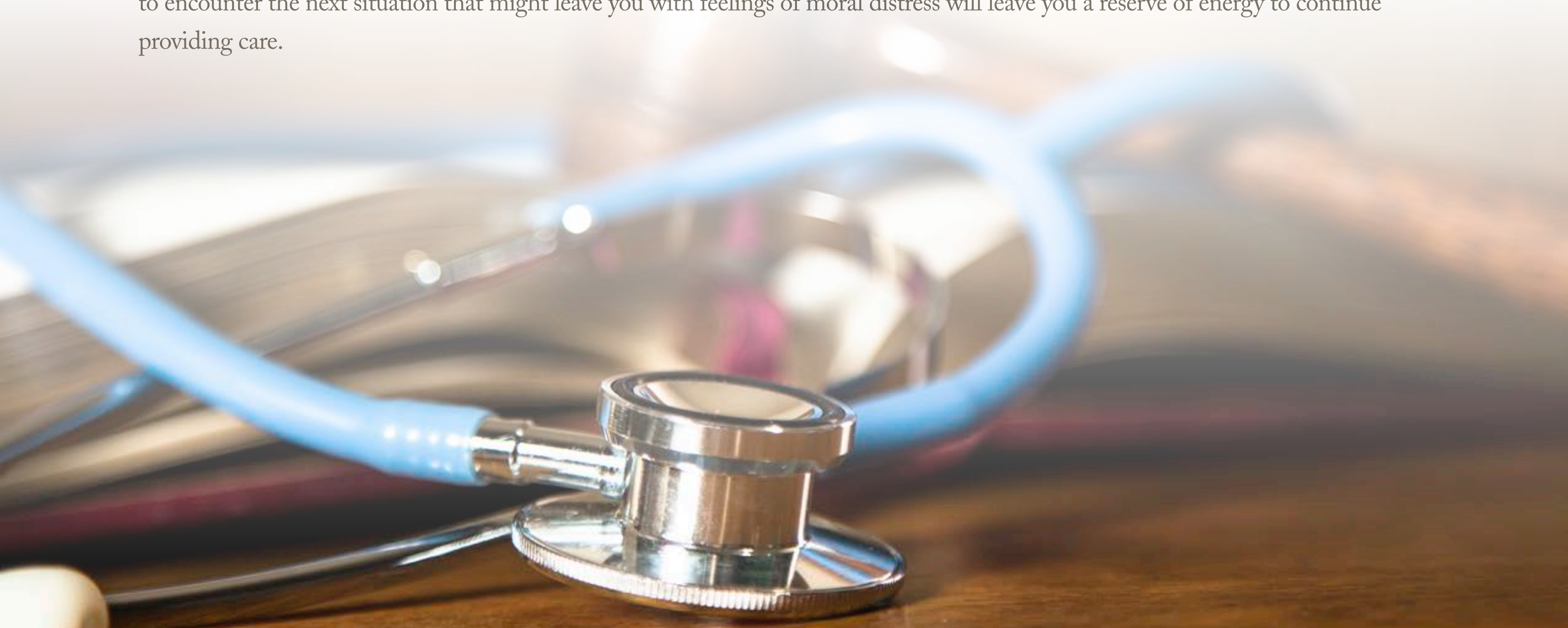
When you recognize that the distress you are feeling following a provider-patient encounter raises ethics-related questions, then you have made an important first step toward ensuring the delivery of ethically reasonable and permissible treatment and care. When you experience conflict between personal and professional values,—such as meeting the expectations of institutional requirements, or facing decisions made by other team members, patients or their decision makers—you can become a catalyst for change.[2]

Your awareness of moral distress can be used as an indicator for improving care. Seeking ways to communicate your perspective, grounded in ethical reflection and reason, could help clarify ambiguities and reveal alternative choices.

This is one of the benefits of a strong palliative care approach; rarely is there one point of view, but what is often revealed is the overlap of values that when shared can reveal the best, most acceptable choice in light of a pursuit of good. Accept what you cannot change at the time and bear in mind what you can do for yourself, the patient, and their family:

- Invite those involved to engage in conversation, with assistance if necessary (use a translator if relevant)
- How can you prepare to better understand values others have?
- Have another discipline present if information or advice is outside your purview
- Are you comfortable with issues that require practice in ethical reasoning and the language to support differing perspective?
- Take the time to make sure all parties are fully informed and have had their questions and concerns addressed. (e.g. Consider asking if there is something the patient wants that is being denied or ignored? Are your concerns being denied or ignored?)
- Consider during conversation what is the root cause of your feelings of distress?

Make certain to complete a patient/family/provider conversation by charting the decision-making process and outcomes, including the ethical reasoning. Keep track of your own notes so as to build resilience through repeated experience. Being better prepared to encounter the next situation that might leave you with feelings of moral distress will leave you a reserve of energy to continue providing care.



When Limited Resources Lead to Moral Distress

Moral distress can sometimes occur in the sphere outside direct patient care and family decision making. Situations exist where limited resources can hinder or prevent a provider from delivering what they consider the best care and treatment.[4] Resources can include access to necessary equipment, pharmaceutical products, shift relief, availability of other healthcare disciplines, transition of responsibility, and even education.

There are many causes for limited resources; resolution might be outside the bounds of your authority but understanding the source can help you feel less out of control. These following examples of issues that could lead to moral distress are realistic and reasonable:[6,4]

- Frustration created by a pattern of scheduling that has created repeated scenarios where staff shortages have affected patient wait times and extended their discomfort
- Recognition of the infrequency of end-of-life conversations (when pressed for time, the conversations necessary to advance better understanding of prevailing issues and move toward consensus on decision-making are simply not held)
- Cutting budget resources to train and educate about effective communication techniques.

When Less is More: Knowing When to Introduce Palliative Care

Consider the issues in the following scenario that might become sources of moral distress and keep in mind when a palliative care conversation might be offered.

At 98 years old, Mrs. K had keen eyesight, was sharp-witted, slightly hard of hearing in her right ear, still went to the YMCA twice a week for adult exercise class, and had made a time-honored pie recipe for her husband every anniversary of their 76 years together. It was her heart, of all things, that had become increasingly weaker over the past year.

The diagnosis was CHF; accompanying her on this latest appointment were her husband and two of her four daughters. They were well informed and up-to-date regarding the prevailing symptoms and noticeable aspects of physical decline due to her weakening heart. Mrs. K's medication, use of pressure stockings, and attention to a careful diet had become parts of a regular regimen. It was clear that Mrs. K and her family members had been participants in the regular, but increasingly frequent, appointments.

After completing your initial assessment, Dr. H enters the room, offers a brief introduction as her new cardiologist, makes a few comments about her general health status, and proceeds to state, "I recommend a TAVR; this procedure will make you comfortable, provide better breathing, and overall extend your life by months, if not years." Knowing the scheduling challenges and patient loads

facing the hospitalists, it is still difficult to observe and listen to the speed with which he addressed Mrs. K and her family. They listen respectfully.

The daughters ask about the risks involved in the procedure, and the length and challenges of recovery. They also ask about the success rate of the procedure in people in their mother's age bracket. Dr. H checks his watch, responds, "She should have no trouble with surgery or recovery; we perform these procedures often. Let me know if you have more questions, and then we can move forward with scheduling the procedure."

Imagine having listened to this exchange and watched the encounter unfold. Would you have handled the exchange differently? Are there signs of distress tugging at your own heart?

This scenario describes several possible points where feelings of moral distress might surface. The patient seems to have been the recipient of good health complemented by quality care provided by her family and healthcare providers. The amount of care provided seems to have been adequate in managing her prevailing symptoms.

While listening to the delivery of information from Dr. H, however, you sense a sudden inconsistency in the care plan. Is the patient and family sufficiently informed to make a choice for the procedure? At 98 years old, shouldn't the risks inherent in a heart procedure be better presented and explained to the patient? Is the heart procedure a real benefit in the context of quality of daily living? Have you just experienced an example of poor communication between physician and patient/family group?

Is time between patients such a limited resource that Dr. H doesn't have time to spend with the family? Has this been a missed opportunity to introduce palliative care and possible end-of-life decision making? Why didn't Dr. H ask about advance care planning? Are you concerned that Dr. H would not have been receptive to your questions or concerns? How would Dr. H have reacted if the family had requested more appointment time to explore their concerns and gather more information?

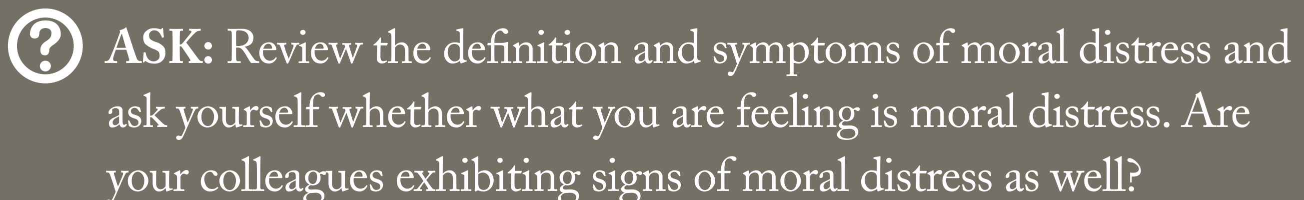
What could you have done differently? Where would you turn to alleviate the sense of distress that is brewing?

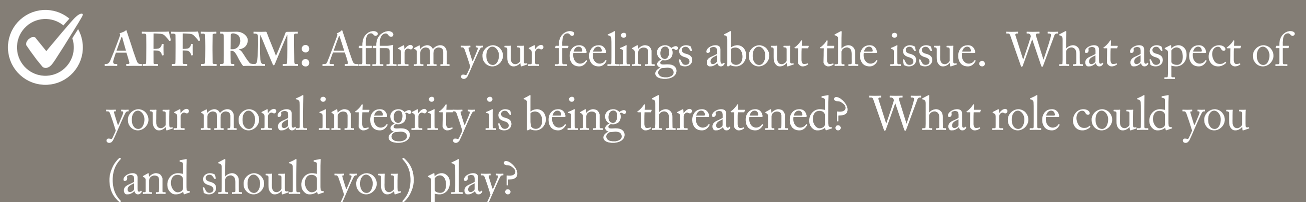
Strategies for Addressing and Relieving Moral Distress

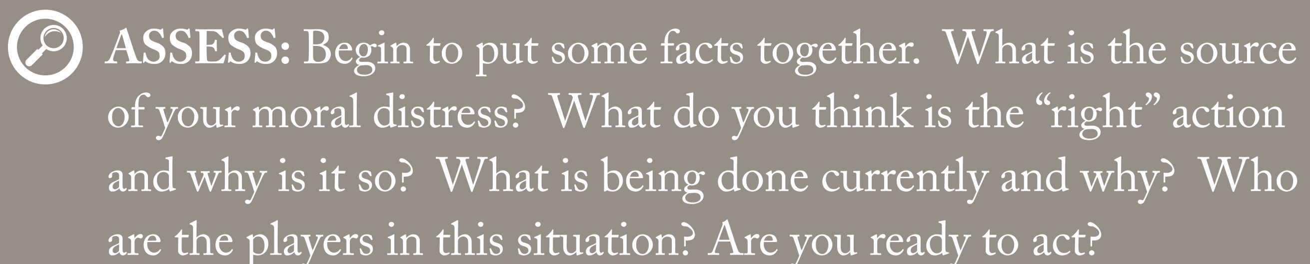
Communication is an essential component of caring for people living with serious illnesses. It is equally essential to addressing, preventing, and relieving moral distress. Find opportunities to engage in discussions where new values can be revealed. Engaging patients and families to explore new perspectives on their illness can result in preventing unwanted procedures, identifying those with diminishing benefit, and avoiding unnecessary harm. A consequence of living with advanced disease or the limitations of aging is a shift in what is valuable or important to the present.

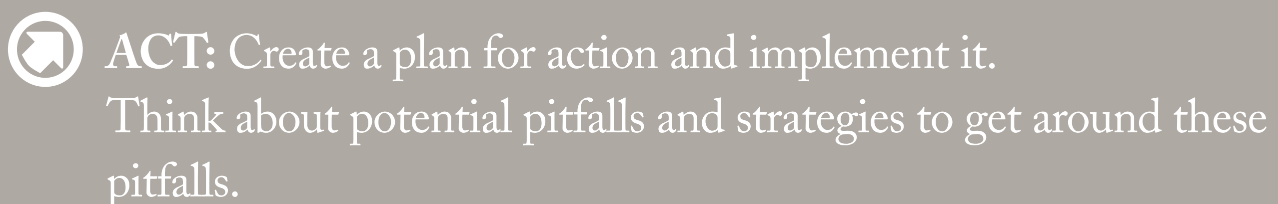
Several approaches to reducing moral distress have been researched and applied.[3,5] The American Association of Critical Care Nurses have created the 4 A's approach to address and reduce moral distress: **ASK, AFFIRM, ASSESS,** and **ACT.**[3,5]

The 4 A's approach to address and reduce moral distress:









Be deliberate and reach out to a peer, seek advice from a lead, or speak to a source of advice on ethical issues when you find yourself harboring moral distress. Having confidence in your moral compass is essential; it can help you see another's point of view without diminishing your own. Seek education that will better inform you on ethical issues, perspectives, and provide the tools for reflection and reasoning. Distress involves emotions but it can be managed with reasoning, exercising the ability to reason with others, and learning to avoid engaging in opposition.

In essence, use your voice to identify what is distressful by asking questions from all parties involved. Seek greater understanding and appreciation for the diversity of values that surface during difficult conversations and decision making, especially during times when the quantity and quality of life itself is part of the equation.

Returning to the scenario where you have witnessed the patient, Mrs. K, being offered a cardiac surgical procedure, what about this scenario might cause you to experience moral distress?

Identify the possible value conflicts and resolutions:

- If Mrs. K and her family were not provided with a reasonable description of the procedure, including its risks and benefits, can you recommend a second visit? How do the surgical risks and benefits measure in regard to the quality and quantity of her life? Can you ask if they have heard about palliative care?
- What if Mrs. K declines the procedure? Who will follow-up on continuing a goals of care conversation?
- Should Dr. H have taken more time with Mrs. K and her family? How would you go about making this happen?

Remember you have resources to use to be ahead of any feelings of distress that might linger from witnessing this type of challenging interaction. Take time to identify the issues, make notes of your own, speak to someone else, and seek ways to strengthen your ability to either affect change or remain confident in your own values when you cannot.

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Conclusion

Acknowledging that medicine is a moral pursuit, moral distress can be accepted as an inevitable part of providing healthcare. Understanding and addressing moral distress is important for anyone working with seriously ill patients and families. They stand a greater chance of experiencing moral distress because their work invariably demands confronting the vagaries accompanying unpredictable and difficult treatment outcomes, and increasingly ambiguous goals of care.[4]

Having the wisdom to accept the myriad of different opinions others hold is a big step toward understanding conflict. Accepting that even if a decision is made that does not match your own sense of what is right, it might be right for someone else. Learning more about differing perspectives will help when you encounter it again; it does not diminish your own ethical views.

Finding the ways to manage your own moral distress will free you to be a better provider of patient care. Ultimately, your time spent with a given patient will be but the tick of a second hand on the clock of their existence. Do what you can to make it valuable.

About the Author

Therese Trebaol, D.Bioethics, specializes in clinical ethics consultation. While completing her doctorate in bioethics from Loyola Chicago University, she focused on clinical ethics, palliative care, and end-of-life issues. This led to developing and managing a grant-funded palliative care program at Good Samaritan Hospital in Los Angeles, California. Making the role of a clinical ethicist a key component of an interdisciplinary palliative care team, Therese was successful in demonstrating clinical ethics as an integral aspect of providing quality care to patients and families during times of complex decision-making. She recently worked as the interim Director of Bioethics at Kaiser Permanente in Woodland Hills and is currently writing a course on pediatric ethics for the CSU Shiley Institute for Palliative Care.

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Resources

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