

Understanding Experiences of Moral Distress in End-of-Life Care Among US and UK Physician Trainees: a Comparative Qualitative Study



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BACKGROUND: Moral distress is a state in which a clinician cannot act in accordance with their ethical beliefs because of external constraints. Physician trainees, who work within rigid hierarchies and who lack clinical experience, are particularly vulnerable to moral distress. We examined the dynamics of physician trainee moral distress in end-of-life care by comparing experiences in two different national cultures and healthcare systems.

OBJECTIVE: We investigated cultural factors in the US and the UK that may produce moral distress within their respective healthcare systems, as well as how these factors shape experiences of moral distress among physician trainees.

DESIGN: Semi-structured in-depth qualitative interviews about experiences of end-of-life care and moral distress.

PARTICIPANTS: Sixteen internal medicine residents in the US and fourteen junior doctors in the UK.

APPROACH: The work was analyzed using thematic analysis.

KEY RESULTS: Some drivers of moral distress were similar among US and UK trainees, including delivery of potentially inappropriate treatments, a poorly defined care trajectory, and involvement of multiple teams creating different care expectations. For UK trainees, healthcare team hierarchy was common, whereas for US trainees, pressure from families, a lack of guidelines for withholding inappropriate treatments, and distress around physically harming patients were frequently cited. US trainees described how patient autonomy and a fear of lawsuits contributed to moral distress, whereas UK trainees described how societal expectations around resource allocation mitigated it.

CONCLUSION: This research highlights how the differing experiences of moral distress among US and UK physician trainees are influenced by their countries' healthcare cultures. This research illustrates how experiences of moral distress reflect the broader culture in which it occurs and suggests how trainees may be particularly vulnerable to it. Clinicians and healthcare leaders in both countries can learn from each other about policies and practices that might decrease the moral distress trainees experience.

KEY WORDS: moral distress; house staff; resident; ethics; end-of-life; trainee.

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INTRODUCTION

As front-line clinicians, physician trainees are particularly vulnerable to moral distress, which adversely affects both them and their patients.^{1–4} Moral distress occurs when a clinician is unable to act in accordance with their ethical beliefs due to external constraints, particularly those related to hierarchy or institutional culture.⁵ Historically, the topic has been explored primarily among nurses,^{1,6–8} while few studies have been conducted among physicians.² Physician trainees are particularly vulnerable to moral distress as they are front-line clinicians less empowered than attending physicians to make difficult clinical decisions, they carry out potentially distressing resuscitation and procedures, and they typically spend more time with patients and families than attendings. They are also subject to hierarchical and institutional constraints that can make it difficult for them to deliver care consistent with their own ethical and professional values.⁹ Moral distress contributes to burnout^{3,9} as well as to suboptimal patient care.^{4,10–12}

End-of-life care is ethically complex, particularly when patients are unable to articulate their preferences for care and surrogates are asked to represent the patient's wishes. Patients or families may desire treatments that clinicians deem medically inappropriate or that they would not wish for themselves, a tension which can also contribute to feelings of distress. Delivering potentially inappropriate high-intensity treatments at the end of life particularly contributes to clinician moral distress.^{2,3,13–16}

When comparing the US and the UK, there are institutional and societal differences in how patient autonomy and a patient's best interest are prioritized in end-of-life decision-making. Historically and culturally, the US tends to prioritize patient autonomy, while in contrast, the UK generally

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prioritizes a patient's best interest.^{17,18} In this context, autonomy represents a prioritization of a patient's individual choice and agency, while best interest here refers to actions that adhere to the Beauchamp and Childress principles of beneficence (acting to benefit the patient) and non-maleficence (avoiding actions that harm the patient).¹⁹ A deeper understanding of the way physicians in the US and the UK conceptualize end-of-life care and how divergent ethical prioritization of their health systems informs end-of-life decision-making may help us better contextualize the moral distress that trainees experience.

To our knowledge, no studies have been conducted that characterize experiences of moral distress among physician trainees in the US and the UK. This analysis has two aims: first, to identify cultural and institutional factors in the US and the UK that may produce moral distress within their respective healthcare systems, and second, to compare how these cultural and institutional factors shape experiences of moral distress in providing end-of-life care among physician trainees in the two countries.

METHODS

Design

This is an exploratory qualitative study that was explicitly designed to understand the moral distress that physician trainees experience in end-of-life care. This work is also a subset of a larger study investigating clinician practices and perspectives around potentially inappropriate high-intensity treatments in end-of-life care. The study was approved by the IRB of the University of California, San Francisco.

Sample

Thirty physicians were purposively sampled by stage of training and gender to provide a wide range of perspectives and experiences. We used email list-serves in the US and a snowball sampling strategy in the UK, recruiting residents (US) or junior doctors (UK) in internal medicine or a medicine subspecialty. One researcher (SRM) interviewed 10 UK participants in July–August 2019 and 16 US participants in September–October 2019. Another researcher (ED) conducted 4 UK participant interviews in May 2016 (the temporal gap was due to a lack of funding and personnel), for a total of 16 residents at one US institution and 14 junior doctors at a variety of UK institutions, all of whom completed a process of informed consent. All participants practiced at established academic medical centers. Residents were eligible in the US, and all junior doctors below the level of consultant (including foundation doctors and specialty trainees) were eligible in the UK.

Data Collection

Researchers conducted semi-structured in-depth interviews with physician trainees in the US and the UK. The initial

interview guide was created through a review of the literature and prior research, and revised and adapted throughout the interview process. Theories and hypotheses developed in initial interviews were explored and validated in subsequent ones. Interviews were 40–70 min long. The interviewers asked trainees about their experiences with end-of-life care and decision-making, as well as about their familiarity with the concept of moral distress, and their experiences of moral distress in providing care for patients at the end of life. If they were not familiar with the term “moral distress,” it was defined for them. Interviews were conducted in-person, via Zoom video conferencing, or via phone, in accordance with the participant's preference. Interviews were audio-recorded, transcribed verbatim, and anonymized. Data collection and analysis occurred simultaneously throughout the interview process. Data collection was completed when theoretical saturation occurred, such that the same themes recurred and no new themes were generated.²⁰

Analysis

The work was analyzed via thematic analysis.²¹ We used a mixture of inductive and deductive analytic approaches, starting with a related codebook developed by the study team (ED, JNB, TM, DD) in the larger study on clinician attitudes around high-intensity care. We refined and tailored the codebook to this particular study throughout the coding process, adding codes that emerged in the data and were not captured in the existing codebook. Coding occurred in ATLAS.ti. Twenty percent of the interviews were double coded by two researchers, ED (a physician and sociologist) and SRM (a fourth-year medical student), with rare disagreements, which were resolved in discussion. The remainder of the interviews were coded by SRM. After generating initial codes, the team worked together to collate codes into potential themes, prioritizing those that were frequently mentioned. The scope and definition of each theme were refined in reference to the data to inform the results presented here.

RESULTS

A total of 16 physician trainees participated in the US and 14 in the UK (see Table 1).

Table 1 Participant Characteristics

	US (n = 16)	UK (n = 14)
Sex: M, F	6, 10	4, 10
Age in years: mean (range)	30 (26–39)	30 (27–34)
Years of experience: mean (range)	2.2 (1–3)	3.6 (2–6)

US residency training typically lasts 3–7 years, and UK junior doctor training typically lasts 5–8 years. In the first 2 years of training, UK junior doctors are referred to as foundation doctors (F1, F2), after which they work as a specialty registrar in either general practice or a hospital specialty for 3–6 years (ST1–6).

We identified many factors that participants perceived as contributing to moral distress. These drivers of moral distress function as external constraints that make it difficult or impossible for clinicians to act in accordance with their ethical beliefs. We divide the results in two sections—structural drivers of moral distress that were similar, and those that were different between the US and the UK. Some, such as delivering potentially inappropriate treatments, were similar between US and UK respondents, while others differed, such as disempowerment within the healthcare hierarchy or pressure from families.

STRUCTURAL CONSTRAINTS THAT WERE SIMILAR DRIVERS OF MORAL DISTRESS BETWEEN THE US AND THE UK

Potentially Inappropriate Treatments

Most physician trainees in both the US and the UK felt moral distress around providing treatment they perceived as potentially inappropriate. They commonly described the way treatments prolong suffering and the complicated role families play:

It was clear that she was dying, and we created an option for something that I think was medically inappropriate, but also, there's a tremendous moral component of prolonging suffering in someone, and allowing decisions to be made by families that don't understand that there isn't a better end point. (US, PGY3)

One stated that she felt that the bulk of her job was spent delivering interventions unlikely to have an effect:

I just really think a lot of the job of a [junior doctor] is running around, trying to save people who don't, you're not going to save, doing ABGs [Arterial Blood Gas] and things on people who are going to die anyway. I just feel like it's very futile and quite distressing to everyone, including us, and the nurses, and the patients. (UK, F2)

Poorly Defined Care Trajectory

Many participants described how terminal patients often initially received all available disease-directed treatments and may progress towards receiving only palliative treatments as their disease progressed. Trainees frequently reported feeling moral distress when treating patients who were receiving neither active treatment nor palliation and whose plan of care was not well defined. This tension is sometimes unavoidable, including times where a patient's disease trajectory is unclear. However, it most often arises when there is a lack of consensus among the patient, family, and clinical team about the type of care a patient should receive.

[There was] a week to two weeks where he was neither actively managed nor was he particularly palliated, and the nursing staff therefore didn't quite know how to treat him, which is a big problem because they spend the most time with him. So, was he being escalated [given more aggressive interventions] in time? Probably not. Were his PRN's [as-needed medications] being given to him properly? Probably not. (UK, ST3)

Involvement of Multiple Teams Creating Different Treatment Expectations

Some respondents spoke about how, as physicians on the patient's primary treatment team, they felt less able to withhold or withdraw treatments than other teams. One described a code as a procedure, comparing it to other procedures that surgeons can withhold:

One thought that struck me was like the surgeons aren't offering surgery. It's interesting that we don't view like codes [resuscitation] the same way because it is a procedure in a sense. (US, PGY3)

One participant spoke about the way in which different specialties can create different expectations about end-of-life care. She described her experience of oncology specialists helping to de-escalate care:

I think in oncology ward it's much easier to talk to people about decision making and ceilings of care... I guess terminal diagnosis, and people expect to deteriorate and expect it to get worst. So sometimes it's easier to have those conversations. (UK, F2)

Trainees spoke about the distress they experienced when the involvement of multiple teams prolonged an ineffective course of treatment:

Chemotherapy was dangled in front of him as this possible carrot where if you better recover from his pain or did better in the future, he may become eligible for it again ... multiple teams were involved and the fact that the patient really wanted some help perpetuated this very, very long hospitalization where there's always this thought well maybe in a week or in a couple of days chemotherapy would be offered. (US, PGY2)

DIFFERENT STRUCTURAL CONSTRAINTS THAT DRIVE MORAL DISTRESS BETWEEN THE US AND THE UK

Disempowerment Within Healthcare Hierarchies

Many UK respondents described hierarchy as a driver of moral distress, whereas few US trainees did. Some UK

respondents described difficulty with raising concerns to their consultants (attending) or suggesting an alternative course of action:

I guess at the end of the day, their names are on the records and everything, and they're worried that we haven't tried everything. Yeah, I've had quite resistant consultants before. (UK, F2)

US participants, by contrast, generally felt empowered to speak up to their attendings if they felt a patient's care was too intensive:

I think when it's explicitly about an end-of-life discussion, I think most of the attendings have been pretty open about at least engaging in a back and forth about that so that I feel like we're both ... I don't think we've ever reached a point where they pull rank and say, no, we're doing this. (US, PGY3)

Pressure from Family

Most US respondents spoke extensively about the moral distress they experienced when a patient's family advocated for more intensive measures than the physician thought medically appropriate or in a patient's best interest. Relatively few trainee respondents in the UK spoke about distress caused by pressure from families. US respondents spoke about how family members often prioritized their own wishes over those of the patient themselves:

I think that gets tricky, especially when other people become involved. I think I had an ICU attending who called it 'the nephew from Peoria,' the family member who shows up and has not been involved at all and is just like, 'What are you talking about? How could you kill my family member?' (US, PGY3)

Another resident spoke about the challenge of family members who wanted to reverse a patient's "code status," when the patient was incapacitated. "Code status" refers to the level of intervention a patient wants if their heart or breathing stops (e.g., "full code" or "Do Not Resuscitate").

There have been a handful of instances where the family will be like, "This is their POLST [Physician Orders for Life-Sustaining Treatment, a medical document that outlines treatment preferences], and we're reversing the code status," because now it's happening in front of them. I think we always tell patients, "The code status is something that can change at any time," but it's hard I think the first moment when you capture the patient unable to communicate and the family is put in the position. (US, PGY2)

Distress Around Physically Harming Patients

Many US respondents explicitly referred to the physical trauma that clinicians inflict upon patients in providing aggressive treatments, whereas few respondents in the UK mentioned the topic. US trainee respondents spoke about the way in which the physical labor of performing futile resuscitations caused psychological trauma:

It is so distressing. You are beating someone's body, and often as the medical provider, you personally are beating their body... It is very difficult to go home at the end of the day and be like, "I just did this. I just battered someone today." (US, PGY3)

Systems and Guidelines that Facilitated or Hindered the Ability to Withhold Potentially Inappropriate Treatments

Many UK participants spoke about guidelines for the use of life-sustaining treatment that made it easier to withdraw or withhold potentially inappropriate treatments:

I think they've got strict criteria [for dialysis] which probably helps... There are certain other things to qualify and if there's quite strict rules it's easier for doctors to say, "Sorry, you don't qualify." (UK, ST2)

In contrast, US respondents described the lack of guidelines for interventions at the end of life. This physician specifically contrasted the system in the US to that in the UK, describing how the individual physician rather than the health system bears more responsibility for making decisions about the limits of treatment at the end of life:

I think it's really hard because as a society we have not really made decisions about how to weigh those against each other. Whereas other societies, for example the National Health Service (NHS) in Britain have made it really clear that certain end-of-life, certain procedures, sort of interventions at the end-of-life will just simply not be covered by the national health care system... So I think as a society we need to kind of have these types of conversations more, so that the burden isn't on an individual [doctor]. (US, PGY3)

ROLE OF SOCIETAL CULTURE

Most US respondents described how societal culture contributes to moral distress, whereas most in the UK described how societal culture mitigates it.

Patient Autonomy

Trainees in the US described how the health system's prioritization of patient choice contributed to the difficulty doctors

face in delivering potentially inappropriate treatments at the end of life:

In other countries for example, people aren't even offered at all and that's just the culture of that country and how they approach end-of-life care. Whereas here we give the decision totally to the family or the patient. (US, PGY3)

Fear of Lawsuits

Trainees in the US endorsed widespread concern about lawsuits among their colleagues, though nobody reported knowing someone who had been sued for withholding or withdrawing care at the end of life:

I think there's kind of like the liability culture that we live in where sometimes I think people want to be like, "Well, you could do this or this or this," and just putting the burden on the patient, takes the responsibility off the physician. But I don't think that that's actually better for the patient. (US, PGY1)

Resource Allocation

US trainee respondents spoke rarely about resource allocation in the setting of end-of-life care, whereas many UK respondents spoke explicitly about patient understanding that the NHS had limited resources as a mitigator of moral distress:

I think people are much more understanding than if you were to talk about it in a different healthcare setting... If you explain to people that there's a resource issue, or that things will take time, and they get frustrated, but they understand. (UK, ST2)

DISCUSSION

Our research highlights the ways US and UK physician trainees experience moral distress differently, informed by their respective countries' healthcare cultures. This research illustrates how experiences of moral distress reflect the broader institutional and social climate in which it occurs and suggests how trainees may be particularly vulnerable to the experience of this distress.

Trainees are particularly vulnerable to moral distress in the delivery of end-of-life care.^{2,22,23} Many causes of moral distress among clinicians are documented in the literature, including providing care not in a patient's best interest,²⁴ poor patient care due to lack of continuity or poor communication,²⁵ and poor patient care due to time constraints,²⁶ but the most common cause described is aggressive and perceived futile treatment, particularly at the end of life.^{2,13-16} Potentially inappropriate high-intensity treatment near the end-of-life is also known to decrease patient quality of life.^{27,28} This study

contributes to the literature by identifying and characterizing additional drivers of moral distress that are common or distinct among physician trainees in the US and the UK. By identifying successful practices that are common or accepted in the UK, but not found in the US, we can help identify practices and policies that alleviate moral distress and improve end-of-life care that exists in the UK that could be introduced in the US context.

Several drivers of moral distress described in this study were endorsed by trainees in both the US and the UK. Concern about potentially inappropriate treatments at the end of life is consistent with the existing literature, but the themes of care trajectory and ability to withhold treatment are less well characterized. A patient's care trajectory may be poorly defined for multiple reasons, some of which may be more likely to cause moral distress than others; for example, sometimes a trajectory is poorly defined because of poor communication within a team, whereas other times it is poorly defined because families may need time to come to terms with a loved one's impending death. It is likely that these drivers were consistent between the two countries because they pertain more to the type of treatment given at the end of life than to the systems and structures in which the treatment is given.

Non-beneficial treatment at the end of life is widespread in many countries,²⁹ but its prevalence and definition vary based on many factors, including national³⁰⁻³⁴ and institutional culture,³⁵⁻³⁹ which affect clinician decision-making. In the US, a greater degree of aggressive care at the end of life is more often considered appropriate than in the UK.

In terms of medical culture, many UK participants, but few US respondents, noted that hierarchy within the healthcare system contributed to their feelings of moral distress, often in cases in which they felt unable to effectively advocate for less intensive care for a patient. Hierarchy is a commonly reported reason that UK junior doctors do not feel comfortable speaking up in clinical situations, which contributes not only to moral distress but also to medical errors and poor patient safety.⁴⁰⁻⁴⁵

We also noted differences between the US and the UK contexts in terms of structures and practices that facilitate withholding potential inappropriate treatments. For US participants, a lack of national or institutional guidelines to stop escalation of potentially inappropriate treatments contributed to moral distress. In contrast, the UK has a robust set of national guidelines that inform end-of-life decision-making, the presence of which helps trainees feel able to resist pressure from families for potentially inappropriate treatment. The UK's National Institute for Health and Care Excellence (NICE)⁴⁶ issues guidance about eligibility for various treatments in a variety of medical settings, and physicians rely on this guidance when offering or withholding treatment at the end of life.⁴⁷ This difference is reflected in different societal and legal norms in the two countries. For example, the UK has significant legal rulings that create public precedents around futile care and limits of acceptable medical treatment, while

the US lacks similar standards.⁴⁸ In addition, in the UK, the physician, rather than the family, has the ultimate authority to make treatment decisions for patients without decisional capacity at end of life,^{48–50} which may contribute to the decreased pressure UK trainees endorsed feeling from families. In the US, the framework of substituted judgment places the decision-making for a patient without capacity in the hands of the family.⁵¹

Finally, broader societal and cultural norms in US and UK appear to affect moral distress. In this study, UK physicians described how a common understanding about the importance of resource allocation helped physicians and families reach an understanding about the appropriate treatment for a patient at the end of life. This likely reflects the strong public image of the NHS as a shared but limited resource. In the US, by contrast, a mentality of consumerism and individual choice drives high-intensity care.⁵² We found that increased family pressure contributed to moral distress experienced by US participants. This increased family pressure in the US relative to the UK is likely attributable at least in part to the different healthcare expectations that patients have in each country.⁵² In addition, prioritization of patient autonomy and a fear of lawsuits further contributed to the moral distress US trainees experience in trying to avoid potentially inappropriate treatments.

Some research exists on ways to combat physician moral distress, including wider adoption of Schwartz Rounds, which focus on the shared humanity of both patients and clinicians.^{53,54} Other options include the implementation of specific clinical practice frameworks and educational programs aiming to help clinicians reframe the ways in which they think about distressing situations.^{55–57} This study also presents opportunities for clinicians in both countries to learn from each other about policies and practices that might decrease the moral distress trainees experience, while also decreasing potentially inappropriate treatments at the end of life. For example, by adopting more guidelines for defining appropriate care at the end of life, US hospitals could enable their residents, with proper supervision, to more easily withhold or withdraw potentially inappropriate treatments at the end of life. UK hospitals could work to decrease the role of hierarchy, especially around end-of-life decision-making, such that UK trainees feel more empowered to speak up if they disagree with a patient's treatment plan. This research underscores the importance of further understanding the impact of potentially inappropriate end-of-life treatments on moral distress and creating guidelines around the provision of appropriate end-of-life treatments to address both quality of end-of-life care and physician moral distress.³

Limitations of this study include social desirability bias in interviews with physician trainees. In addition, we only interviewed trainees at academic medical programs, which may affect the types of clinical cases that trainees encounter and may also have more structures like Morbidity and Mortality Rounds, conferences, or other opportunities to reflect on their experiences of moral distress. In addition, participants came from one site in the US and multiple sites in the UK. This

limitation is partially mitigated by the fact that this study investigated moral distress experienced by the individual physician and did not seek explicitly to understand factors affecting moral distress that varied by institution.

A focus on clinician moral distress is even more important now in the setting of the COVID-19 pandemic. Given a growing scarcity of resources, the pandemic creates a setting in which explicitly rationing care—whether personal protective equipment, hospital beds, or ventilators—becomes necessary, prompting ethical dilemmas and inevitable moral distress. Other aspects of pandemic response, including clinician burnout, infection of healthcare workers, and witnessing increased sickness and death, can all also contribute to moral distress. As we address the physical health consequences and public health ramifications of the pandemic, we must also pay keen attention to the moral distress clinicians experience in these times. Developing clear ethical guidelines for allocation of scarce resources⁵⁸ and robust strategies to mitigate moral distress⁵⁹ in the setting of this pandemic is a crucial first step.

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Compliance with Ethical Standards:

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