

Episode: *Ethics Talk: How Should We Keep Psychiatric Patients Comfortable?*

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[mellow theme music]

TIM HOFF: Welcome to *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics in health and health care. I'm your host, Tim Hoff. This month we're discussing palliative psychiatry. While it's true that all general medical, surgical, and psychiatric patients deserve palliative approaches to their care, palliative psychiatry deserves special clinical and ethical attention as an emerging field that promises to renew attention to patients whose illnesses, such as treatment-resistant depression, and symptoms such as persistent suicidality, patients whose illnesses and symptoms challenge our faith in health care as a life-affirming source of hope.

Joining me on the podcast today to discuss how clinicians can prioritize symptom management, relieve suffering, protect quality of life, reduce harm from aggressive interventions, and minimize physical and chemical force in the care of palliative psychiatric patients is Dr Amy Johnson. Dr Johnson is an assistant professor of clinical medicine in the Department of Palliative Care and a key clinical educator in hospice and palliative care at the Indiana University School of Medicine in Indianapolis. Dr Johnson, thank you so much for being on the podcast. [music fades]

DR AMY JOHNSON: Yeah, thanks so much for having me.

HOFF: So, the concept of psychiatric end-of-life care is deeply uncomfortable for some people, including many clinicians. For many, there seems to be an underlying assumption that psychiatric illness should never be conceived of as a terminal illness. This might be because people also assume that if a psychiatrist takes, quote, "good care" of a patient with psychiatric illness such as depression, then that patient's life won't end in suicide. But we also know that there are good reasons to take seriously the idea that depression is, for some patients, a terminal illness. So, help our listeners understand why end-of-life care should be regarded as a key part of the psychiatric care skill set?

JOHNSON: Absolutely. So, just to sort of add on, you mentioned depression. There are several serious mental illnesses that I would say can become terminal. And so, making sure we're talking about anorexia nervosa, schizophrenia, chronic suicidality, those with chronic self-injury, and borderline. Patients with substance use disorder and alcohol use disorder are also patients that I've helped to care for. I feel that as far as this being a skill set, a lot of patients who are cared for, for serious mental illness have very strong relationships with their psychiatry team. And so, over time, I think that it's just very important that this is a concept that we're thinking about in all patients and to provide sort of primary palliative care and that palliative care approach when there's some concern that we're moving towards a life-limiting illness. Psychiatrists need to be comfortable referring to primary or to specialty palliative medicine as it is needed.

HOFF: So, what might careful patient-psychiatrist deliberations about a patient's potential death look and sound like?

JOHNSON: My first initial thoughts to this question are just so, so supportive and so sensitive. You know, most end-of-life conversations and sort of goals of care and thinking about it just need to, they need to start with some open, honest communication and sort of as the provider suggesting, "What are your concerns and kind of why do you even think we need to have this conversation?" Getting some ideas of what the patient's perspective of their illness is. These are where we pull out all of our empathy tools that we can. There's a lot of studies on how to give bad news, and I would imagine sort of presenting this information that, "Despite everything that we have tried, I still worry that maybe we don't have your mental illness under well control, and I worry what the future might look like." And so, making sure this is coming from a trusted provider, it's going to be very similar to telling someone that they have a terminal cancer.

This is the opportunity to open up the conversation about what the patient's hopeful for and what's medically appropriate and what's not anymore, and can you bring all of these things together? It's something that both parties sort of need to discuss and agree that there's refractory therapy, needing to think about co-morbidities and what social support the patient has. It's difficult because mental illness doesn't have a staging system, at least as of yet, that I could find. But it's going to be a very similar discussion as if we were discussing end-of-life from any heart, lung, liver disease. And really, ultimately saying, "I want to choose. I'm focusing on the symptoms. We want to improve your quality of life, and that may or may not involve more treatments, new treatments, or different combination of treatments."

HOFF: The deliberations around a patient's death following refractory depression, for example, are likely to look different depending on the legislative landscape where they're receiving care. I'm not sure exactly what Indiana's Aid in Dying laws are, but could you speak briefly to how that might complicate the discussion between patient and psychiatrist generally, if things like that are an option?

JOHNSON: As far as sort of physician Aid in Dying, we don't have, Indiana is comfortable depending on which health care system you are as far as palliative sedation goes. But it's usually, there's different policies depending on the hospital system in which you're in. I would imagine it would be a lot more difficult when you don't have those specific options. And so, it would be very much like my other conversations with patients that, "I'm going to focus on helping keep you comfortable. We're going to make sure that your symptoms are well-controlled, that you have as much support as possible," to talk about what their death may look like in this state. I've had some patients ask, "Are there states that I can go elsewhere to have more options?" And we talk about how most of the time that's not really a good option or a true option for them, especially if their families are here. And so, it becomes more a focus on what we can do to help improve the symptoms as best we can, and then really more just gently giving expectant counseling as things come up.

HOFF: While these end-of-life discussions are important to this issue, it's common to confuse end-of-life care with palliative care. So, we're going to be sure not to do that here. And to be clear for our audience members who might not know the difference yet, in a curative approach, the goal of care is to modify and cure disease. Whereas in a palliative approach, the goal is to manage symptoms, especially those that disrupt quality of life. Curative and palliative approaches don't have to be mutually exclusive, but it is important for clinicians to have clear goals of care. Also, palliative approaches are not only instituted in end-of-life scenarios. That said, one question relevant to defining what constitutes a palliative approach to psychiatry is this: According to which criteria should a psychiatrist distinguish between a goal of modifying a patient's psychiatric disease and the goal of managing a patient's psychiatric symptoms?

JOHNSON: I wish I could give you an exact criteria that is well-tested and well-studied. And in all of palliative care, this is the golden question of when do we make this transition? A lot of this is going to go back to the discussion about goals of care, the expectations that the provider and that the patient has, and really, a clear discussion about what the suspected prognosis is. We ask this question for all palliative care diagnoses, and a lot of times it just depends on the individual disease process that we're dealing with. So, we're going to have different criteria for a patient with cancer than a patient with end-stage liver disease. I think one of the easiest ones that we use and that actually has been studied is the surprise question, where if the clinician can say, "I would not be surprised if this patient died in the next year," there's actually some pretty good literature to support that as kind of an initial question to ask when we're looking at prognosis.

HOFF: So, let's apply these distinctions between curative and palliative approaches to psychiatry to thinking about end-of-life psychiatric practice. There are a number of ways that clinicians can help patients be more comfortable at the end of their lives. One of those is prescribing helpful drugs. So, how have palliative care clinicians' views about the use of psychopharmacological agents at the end of life changed with the development of more robust psychiatric end-of-life care options?

JOHNSON: Yeah, I think if there are teams that have really strong integration with psychiatric palliative care, I imagine that their comfort has grown exponentially by having the support of that person, but also learning from that person. If we have palliative care groups that don't have strong psychiatric support over the years, we just get more comfortable with these types of medications and sort of just having to do what we need to do for the patient in front of us. I know I became comfortable with a lot of the psychiatric medications out of necessity. I have patients showing up with untreated mental illness and then obviously exacerbated by serious illness and then really needing to act in the moment. So, even if I was able to get them to a psychiatrist, I had to do something, and then getting them into our psychiatry team. So, I think a lot depends on where the patient's being seen and where they're practicing at as far as the comfort with these kinds of medications.

HOFF: Now let's help our listeners understand sedation as one possible palliative approach, one very specific kind of symptom management, even for patients who have attempted suicide. So, what would it mean to use sedation appropriately as a palliative approach to psychiatric patients' care?

JOHNSON: I mean, ultimately, palliative sedation is when we, as the clinicians, and the patients recognize that they are suffering, and it's outside, can't be controlled with anything else that we are doing. We typically think about this more for pain, dysmia, and somatic symptoms, but suffering is very much a subjective complaint from the patient. And I think it's within the provider to decide, is this suffering refractory? Have I done everything else that I can possibly imagine before we consider discussing true palliative sedation? For the palliative care field, this remains controversial between existential suffering and psychological suffering. In our field, there's arguments both for and against. Ultimately, it comes down to decision-making capacity and really starting from there and making sure that the patient truly understands what's going on, which sometimes is hard to see through all of the suffering. But ultimately, unrelieved suffering and we can't control by any other means, we would offer palliative sedation regardless of the diagnosis.

A couple of cases that I thought about where palliative sedation may be something that can be offered. I've had a patient with severe alcohol use disorder, multiple suicide attempts, and repeated self-harms, has no social support, pretty much on his own, very

insightful that this illness is going to end his life, trapped in sort of the emotional distress of living his life like this. And really, there aren't, beyond all the things that we've tried, he would be someone worth discussing what palliative sedation would look like. I've had patients with severe anorexia for decades who were admitted for multiple attempts at artificial nutrition, either TPN or feeding tubes, and just not wanting to continue on getting aggressive medical care and wanting to be able to die peacefully. Other cases I've thought about were patients with several decades history of schizophrenia with high symptom burden, lack of social support. These are all patients that after evaluation of suffering, one could consider discussing palliative sedation as an option.

HOFF: Hmm. Given the importance of clear communication and shared decision making, tell me more about how clinicians might be able to, as you say, see through the suffering in working with their patients to develop goals of care and to assess treatment options?

JOHNSON: Yeah, I mean, obviously if there is care, caring loved ones and families that are available, we would make this into a group discussion and any caregivers that know the patient or other providers. A lot of it's just sort of asking through the decision making, you know, "Do you understand what's going on with you? Do you understand what's been tried? The pros and cons of the current situation at hand?" I think just really a lot of that decision-making capacity and sort of educating and hearing their responses and what is their rationale for what they're asking and what they're suffering through, I think this is going to be a very provider individual of sort of what is accepted as pure suffering.

HOFF: So, in addition to the things we've already covered, symptom management using pharmacotherapeutics, advance care planning, clear communication with family and loved ones of diagnoses, prognoses, and general expectation setting, these are all key parts of good palliative psychiatric practice. So, for students and early career physicians interested in palliative psychiatry, which other skills should they be looking to cultivate?

JOHNSON: I think any time we can continue to learn good sort of bedside patient care, which that can be extrapolated to outpatient, and just really understanding and respecting end of life happens involves respect for the individual you're caring for. We talked about empathy before, but how can we maintain a patient's dignity? And I think one of the things over the years one learns and is hard at the beginning is to recognize that every patient's a new case, and not every patient is going to follow a particular algorithm. And so, I think making sure that you spend the time talking to the patient, asking the patient questions, getting to understand their rationale and their suffering, and you can figure out how you can at least try to help them a little bit. [theme music returns]

HOFF: Dr Johnson, thank you so much for your time on the podcast and for sharing your expertise with us.

JOHNSON: Yeah, thanks again for having me.

HOFF: That's all for this episode of *Ethics Talk*. Thanks to Dr Amy Johnson for joining us. To read our full issue on Palliative Psychiatry for free, visit our site, journalofethics.org. And for all of our latest news and updates, follow us on Twitter [@journalofethics](https://twitter.com/journalofethics). We'll be back next month with an episode on Geriatric Psychiatry. Talk to you then.