

Episode: **Ethics Talk – Why “Palliative Surgery” Is Not Like “Jumbo Shrimp”**

Guests: Alessa Colaianni, MD, MPhil and Wynne Morrison, MD, MBE

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[chill 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. To many, including some clinicians, palliative care is synonymous only with end-of-life care. Palliative care is thought by many to mean what you do when, as the terrible saying goes, "There's nothing more we can do." The truth is clinicians should probably never say there's nothing more we can do. For many patients, palliative care is a regular, critical part of good clinical care management. Regardless of whether curative interventions are off the table or not, palliative care should, in many cases, still be considered, cautiously considered that is.

Another myth about palliative care is that it's passive, it's minimally risky, and it's minimally invasive. This isn't always the case. Palliative surgery can be life changing for patients who need symptom relief and improved quality of life.

To explain why she thought a theme issue on the topic of palliative surgery was necessary and what she learned while developing this issue, Editorial Fellow Dr Alessa Colaianni spoke with us last year. Dr Colaianni is an Otolaryngologist Head and Neck Surgeon, focusing on treatment of patients with benign and malignant tumors of the head and neck at Harvard Medical School in Boston, Massachusetts.

So, to begin with, Dr Colaianni, why this topic? [music fades out]

DR ALESSA COLAIANNI: So, I'm an ear, nose, and throat surgeon, and in particular, I'm focused in head and neck cancer. And head and neck cancer is this really devastating diagnosis that can really change the way that people look, feel, talk, swallow, really essential aspects of their humanity. And when head and neck cancer is incurable, the impact on a patient is really profound. And so, over the course of the last five years in residency, I kind of found several cases where people had incurable disease and yet benefited from a surgical intervention in a palliative setting.

So, there's a lot of kind of misconceptions about what palliative care is and is not. A lot of people think of palliative care as just hospice, or palliative care is what happens when you're incurable and you are electing to not pursue treatment. But the goal of palliation is consistent with surgery. So, for example, palliation is more defined by its intent than any specific intervention. And so, surgery can be part of a palliative strategy. And I've seen that work out for patients and not work out for patients over the course of my last kind of five years in residency. And so, it seemed like an issue that was ripe for a little bit more exploration and kind of definition of the ethics around palliative surgery. And when you're doing something very...when you're doing something very potentially morbid for a patient in a non-curative setting, how do the ethics change?

HOFF: Is there anything you've found over the course of your initial research for developing this issue that has surprised you?

COLAIANNI: I think it's been surprising how little consensus there is about even kind of a definition of palliative surgery. So, different people kind of use different definitions in different papers. And the vast majority of papers about palliative surgery are kind of anecdotal, which sort of makes sense. Because it's always a very personalized decision, and the reasons that you're doing an intervention on somebody are very personalized. And so, it's often kind of an anecdotal case-by-case basis that people are talking about. But, yeah, just the lack of consensus, I think, was really surprising to me.

HOFF: Mm. And I would guess that the way that you measure outcomes is different than a curative surgery, for example, as well.

COLAIANNI: Yeah. Again, it's very qual— You know, I think it's a very kind of case-by-case basis there, too, because the goals of palliative surgery for one person might be, "I'd like to be able to go out in public" or "I'd like to be able to change my dressings on my fungating wound less often." And so, that would be not necessarily a goal of a curative surgery; that would be an incidental goal. But for palliative surgery, it can be very, very personalized.

HOFF: Hmm. And do you have a sort of working definition for palliative surgery that you have in mind while you're developing this issue?

COLAIANNI: So, yeah. So, the definition that I'd like to kind of use as the unifying definition, at least for this issue, is kind of any invasive procedure in which the main intention is to mitigate a physical symptom in a patient with a non-curable illness and without causing premature death.

HOFF: Great. Thank you. Has learning more about this topic changed the way that you approach health care in your own practice?

COLAIANNI: I think in general, surgery has come late to the palliative game. So, palliative care has grown just exponentially over the course of the last 20, 30 years in America. And I think with that has come an increased understanding and appreciation for symptom-oriented treatments for people. And I think for a lot of surgeons, that seems kind of antithetical to what they do every day. Nobody in surgery would like to think of themselves as a palliative only surgeon. And the goal in most surgeries is to cure or alleviate or. So, I think by virtue of having done a palliative care rotation when I was a medical student, I sort of like already, I was already bought into palliative care. And within my residency program, I think I'm known as somebody who likes to reach out to palliative care, probably earlier than most people and certainly more than my attending [chuckles], more than some of my attendings. So, I wouldn't say that it has necessarily changed my practice, but it certainly kind of sharpened my thinking about why we're doing what we're doing and kind of being honest with ourselves about the goal of a particular operation.

HOFF: Sure. So, building on that, what do you think are the most important takeaways for people who read your issue?

COLAIANNI: So, I think one of the main takeaways is really just to understand that an invasive intervention like a surgery can be a part of a palliative care strategy for a patient with incurable disease and that sometimes that might be the morally imperative or morally correct thing to do. Which seems, it seems a little contradictory that the most morally

imperative thing to do for somebody who has limited time is the most interventional or most morbid thing for them, but that can sometimes be the case.

HOFF: So, what about the future of this topic excites you? Is there any research or advocacy efforts that our listeners should be aware of?

COLAIANNI: Yeah, there's a whole group now on Twitter of surgeons who are involved in palliative care. And it's not just palliative surgery, but any kind of palliation strategy. So, I think the tides are shifting, or at least there's some early adopters that are kind of willing to understand palliative strategies as an integral part of surgical care. So, I'm excited about kind of where that goes. [chill music returns]

HOFF: That was Dr Alessa Colaianni, the Editorial Fellow who helped develop this issue.

Palliative surgery, when compared to the gentle end-of-life care many think of when they think of palliation, might sound like a contradiction in terms. Patients and clinicians need to think carefully when confusion arises around what it means, who it's for, and how it can be used alongside curative treatments. Up next, Dr Wynne Morrison, the Director of the Justin Michael Ingerman Center for Palliative Care, talks about how clinicians can help patients and their families think through these difficult, important questions.

HOFF: Dr Morrison, welcome to the show and thank you for being here. [music fades out]

DR WYNNE MORRISON: Thank you very much. I'm excited to have this chance to talk.

HOFF: In a 2014 article, you and your coauthors described regoaling as a process by which parents of seriously ill children transition from one set of goals to another when their initial goals, such as curing the conditions that a child is experiencing, become increasingly unlikely. As goals change, the boundaries of what are considered appropriate interventions are also likely to change. So, how does surgery fit into the process of shifting goals from cure to palliation?

MORRISON: Surgery is similar to many other interventions in that it's important to really look at the intervention and what you are hoping to achieve with it. Does it potentially meet important goals for a patient or family? How likely is it to do so? What burden is being caused by the intervention itself, and is that something that needs to be considered in whether to pursue a procedure? One thing that is different about surgery is it's almost inevitable that a surgical procedure has at least some burdens or causes some pain and also has a risk of complications. And that is often also true of medical interventions, but a little bit even more so with surgical interventions. And that makes weighing this calculus of how much are we hoping it will help, what are the chances, and how much harm will it cause even more critical for surgical procedures.

The idea that we were talking about in the paper about regoaling is the idea that as any disease process progresses or changes, sometimes the patients and the families have to reconsider what their goals are. And exactly as you said, that could be shifting from hopes for a cure to maybe realizing a cure is not possible. Then there might be hopes for prolonging life and a relatively good quality of life, maybe for a longer period of time, even without a possible cure. And then there could need to be a shift to focusing only on avoiding suffering and treating suffering as much as possible.

HOFF: Mmhmm.

MORRISON: There can be a lot of other goals intermingled in there. There could be goals to make sure that no stone is left unturned. There could be goals to try any available experimental therapy, either for the small chance that it might help the patient or for a chance to contribute to knowledge and help others in the future. There could be goals to be at home and avoid being in the hospital. There may be, alternatively, goals to be in the hospital for a variety of reasons, at different points in care.

HOFF: Mm.

MORRISON: The other thing that can happen is even when goals don't shift, clinical circumstances can change, which makes the decision that's going to be made different even if the goals are exactly the same.

HOFF: Hmm.

MORRISON: So, an example of this might be a patient who has decided that he really does want to focus on comfort at home as much as he can. And one month, that might mean avoiding any surgical procedure and really getting home. But the next month, perhaps a surgical procedure is being offered that gets him more good time relative to the harm it might cause to get back home and spend more time at home. And so, his goals haven't actually changed, but the clinical circumstances and what is being offered has changed. Whereas last month it might've made sense to say no more surgical procedures, the next month there's either a different procedure on the table, or his health status is different that makes it important to reassess at that time.

HOFF: Sure. We tend to think of surgery as particularly aggressive care, and that palliation is a kind of end-game surrender to the natural course of the condition. But palliation can also be aggressively pursued. Like you just said, there can be this sort of no stone left unturned mentality. What might this full tilt, all engines palliation look like? And why might it be important for us to think of palliation in those terms sometimes?

MORRISON: Well, it's interesting. As you are probably aware, some surgical procedures are called palliative procedures, even from the beginning, even for a patient that you hope may have decades left to live.

HOFF: Mm.

MORRISON: So, for instance, some complicated cardiac procedures that will never completely cure a disease. Like surgery for hypoplastic left heart, for instance, may be able to palliate a disease process to give the patient as close to a normal life as possible for years or even decades. So, surgical procedures can absolutely be palliative. And I'm actually, [chuckles] I'm married to a surgeon, so I have an interesting perspective on this at times. Sometimes we have patients who are nearing the end of life, and surgeons are appropriately trained not to cause harm by performing surgical procedures.

HOFF: Mmhmm.

MORRISON: And that may lead them to hesitate to operate on a patient who is nearing the end of life because they don't want the last hours or days of the patient's life to be filled with pain caused by the surgical procedure. They also don't want to be the cause of hastening a death if a surgical procedure has a chance of causing some instability. And

they prefer, appropriately, to consider surgical procedures for those who will have a moderate benefit from it.

So, if I am talking with a surgical consultant about a potential procedure for a patient that, in my mind, I know that this is a palliative procedure with the goal being to improve the patient's life or their quality of life for some reason, for however much longer that might be—and often in these cases we're thinking of weeks to months of time—I will frame it for the surgeon as our hopes here are to give him a better quality of life for the next few months.

HOFF: Hmm.

MORRISON: And anticipate that hesitation on the part of the surgical team of, "Well, isn't this patient dying? Is it really wise to operate," to help them see what we're actually hoping for. And most of the time when framed in that way, my surgical colleagues are very easily able to say like, "Ah, yes, I see. This procedure is to help for the next few months to help them be as good as they can be, and we understand we're not trying to do more than that." And again, they may have particular objections based on better knowledge than I have of the surgical risk, and then that's where our discussion can go. What are the risks, and is it worth offering this to the patient? And how do we frame it for the patient? Do we frame this as a very risky thing to do, or do we frame it as a balanced risk that's probably worth the benefit?

HOFF: So, when a child's family and surgeon and perhaps other clinician, as you just mentioned, in these sort of interprofessional conversations about these surgeries, when these different groups disagree about the utility of an invasive intervention at the end of a child's life, which ethical and clinical values should guide those conversations and that decision making?

MORRISON: That's a great question. I think—and I work in pediatrics, so I'll often say, "the child," but this can be applied to any patient, really—but it's really the best interest of the child or the patient that we often have to consider. And when we are talking about a patient who is making their own decisions, clearly, their preferences are also key, and those are important ethical considerations.

HOFF: Mmhmm.

MORRISON: However, the balance of that is that surgery, it is, one characteristic of surgery that is important to recognize is no one can force a surgeon to operate when they think that they are only going to cause harm.

HOFF: Mmhmm.

MORRISON: And that is somewhat different than if a patient shows up in the Emergency Room. You're obligated to render care, and in fact, you should while you figure out what is going on. But for a surgical procedure where there is time to consider is this going to cause more harm or not, you cannot force a surgeon to do something that they think is only going to cause harm.

HOFF: Mmhmm.

MORRISON: And so, oftentimes for surgical procedures, I think when there is conflict, obviously, a great first step is really sitting everybody down, understand-, making sure everyone's heard the same information, really understanding what the goals and hopes are for all parties, and seeing if we can come to mutually agreed upon goals. But when that is really not possible, obtaining second opinions from other surgeons is often the best next step. And that's really to try to understand, is this an idiosyncratic opinion that there's really no chance this procedure can help the patient? Or is it a surgical consensus by talking to more than one surgeon to determine really, this does sound like something we should not offer? And to try to seek those second opinions in as collaborative a fashion as possible. This is not to try to go around someone, but to say every patient and family deserves a second opinion if that's what they want. And we'll try to facilitate that for them.

HOFF: Hmm. Many of the articles in this month's issue of the Journal, and in fact, the process that you seem to be describing there, this kind of collaborative, deliberative process, involve instances of non-emergent palliative surgery. The idea of emergent palliative surgery might be even less familiar to our listeners than palliative surgery is to begin with. So, can you give us a working definition of emergent palliative surgery and an example or two of when this kind of procedure would be appropriate?

MORRISON: Sure, I can try. So, I often think of the difference between emergent and non-emergent is really, how time sensitive is it?

HOFF: Mmhmm.

MORRISON: It also could include, was this a problem that was anticipated or not?

HOFF: Hmm.

MORRISON: And both of those can impact how long the clinicians and the patient and family have to deliberate. And when things are more emergent, it may mean that the patient and family are meeting team members they've never met before, never interacted with before that are getting brought in because of the emergent nature of the intervention that's being decided. And that can add an extra layer of complexity. As a working definition, I guess I would say that an emergent procedure is one that has not been anticipated previously and is relatively time sensitive.

HOFF: Mmhmm.

MORRISON: And relatively time sensitive could be on the order of minutes, hours, or days. You could still consider something emergent if you have like a day to debate and think about it, I suppose. It at least was unanticipated before that course of events.

And an example. So, I could imagine that, say you have a patient with advanced cancer and have been debating an elective procedure of whether debulking the tumor that's in the abdomen again for a second time makes sense or not.

HOFF: Mmhmm.

MORRISON: But then the patient shows up in the Emergency Department with an intestinal obstruction from the tumor. And all of a sudden, the question has changed to, do we do an emergency operation to try to relieve the intestinal obstruction, whether that's from the tumor or not, even if the team may not know what is causing that immediately?

That is a very different question than thinking about all the pluses and minuses of another surgery to reduce the bulk of the tumor itself. It may be that the intestinal obstruction is still caused by the tumor, or it may be that there's other causes like scarring from prior procedures and things like that. And the way you think about it may be exactly the same in that, what are the possible benefits to the patient? What is the pain and the risk of the surgery? How risky is it? Is there a chance it could shorten life? How sure are we that we can do some good with this procedure? And how worried are we that there can be some harm caused? So, all of those questions are the same, but they maybe require answering in a little bit of a faster time frame.

And sometimes for emergent surgery, the other twist is that it's impossible to have full information.

HOFF: Mmhmm.

MORRISON: So, just like in the example I mentioned, where perhaps the question is, do we operate when we actually don't have enough information to know is this being caused by the tumor, or is this being caused by something else? How bad are things? And does this mean the patient has days, weeks, or months left or even shorter than that?

HOFF: Mmhmm.

MORRISON: Sometimes in emergency situations, you just don't know enough immediately before. You don't have time to go get the MRI scan, for instance, before you maybe have to make a decision about whether to do an intervention.

HOFF: Mmhmm.

MORRISON: And so, I think of those situations as one where sometimes it may, you know, sometimes you intervene to gain more time to be able to have a full picture of what's going on.

HOFF: Mm, mmhmm.

MORRISON: And just because you've done that intervention to gain more time to have a full picture of what's going on, it doesn't mean you can't decide to stop later ongoing interventions if it's become clear that they're not going to help the patient. So, for instance, in the bowel obstruction, we were discussing if the surgical team suspects it may be due to scarring from prior surgery and that if they operate, they may get the patient many more months at home with a relatively good quality of life and that's what the patient would want, then perhaps they choose to operate. But then once they do the procedure, they discover that the tumors actually progressed far more rapidly than any of the imaging had suggested and that there is really nothing more that can be done for that, then the plan may need to shift.

HOFF: Mm.

MORRISON: And it's also possible that, at times, a different procedure becomes apparent as something that may help quality of life rather than the one that had been initially considered. So, for instance, for the intestinal obstruction—and you probably have some articles about this—it might make sense to do something to decompress the stomach like a decompressing gastrostomy rather than doing a massive debulking of a tumor again.

And that can improve the quality of life for the patient for however much longer they have and is not as burdensome as doing a more expensive procedure.

MORRISON: Great. Thank you. What do you think health professions students should know about how palliative interventions can be used alongside curative interventions to care well for patients?

MORRISON: Yeah, that's also a great question because what it really gets at is the idea that palliative and curative interventions can truly be integrated. You don't have to necessarily have an abrupt shift in a patient's timeline of their care from we're 100 percent curative until X period in time, and now we're 100 percent palliative.

HOFF: Mmhmm.

MORRISON: Things can be much more intertwined, and you can have curative care mixed with some life-prolonging but not curative care, mixed with some interventions to improve quality of life, mixed with interventions that are purely comfort-focused and no longer trying to gain more time.

So, I think one important point for students as they begin to think about these things is to realize that that can be complicated. There's not always clear lines. And so, what's important is to get back to what is really important to the patient and try and understand that. And you can do that by asking questions like, "What are you hoping for? What are you worried about?" And really exploring with some curiosity. One question could be, "What would be most important to you if it becomes apparent that time is short or that we're not going to be able to cure this cancer?" But really, really trying to understand, even with some what if type questions, can help a clinician get on the same page as the patient and family, which can really then help that clinician tailor the medical interventions to make recommendations.

And I want to make clear, I strongly believe that clinicians should recommend paths to, or choices, to a patient and family, in many circumstances, rather than just laying a bunch of choices on the table and saying, "You choose."

HOFF: Mmhmm.

MORRISON: The clinicians really do need to offer the medical expertise to help guide those decisions. But they don't set the values. The values and what you're hoping for and what you're worrying about, that comes from the patient and the family. [chill music slowly returns] And then the clinician helps to think, "Which medical interventions stand a chance of achieving what you're hoping for, which ones don't, and which are in conflict with other values that you've told me are important to you."

HOFF: Great. Thank you. Well, Dr Morrison, thank you very much for joining us on the podcast this month and for all your expertise and time.

MORRISON: Thank you, Tim. I'm so glad that the group is putting together this issue. It's a wonderful topic and thank you for having me to talk about these issues.

HOFF: That's our episode for the month. Thanks to doctors Colaianni and Morrison for joining us. Music was by the Blue Dot sessions. To read our full issue on palliative surgery, please visit our site, JournalofEthics.org. And while you're there, be sure to check out our

new Author Interview Series of podcasts available on our site or wherever you stream your podcasts. Follow us on [Twitter](#) and [Facebook @JournalOfEthics](#). And we'll be back next month with an episode on health care and homelessness. Talk to you then.