Treating Heart Failure in Adults with CHD Palliative Care

Announcer: Welcome to the Mayo Clinic Cardiovascular Continuing Medical Education podcast. Join us each week to discuss the most pressing topics in cardiology and gain valuable insights that can be directly applied to your practice.

Dr. Burchill - Welcome back to "Interview with the Experts", a podcast series from Mayo Clinic Cardiovascular Education. I'm your host, Dr. Luke Burchill, and I am leading heart failure care pathway development for adults with congenital heart disease here at Mayo Clinic. And joining me today is Dr. Mei Ean Yeow, who is chair of the Inpatient Clinical Practice Committee. And today we're talking about palliative care medicine, which is a really important topic for our patients presenting with more advanced heart failure. So thank you so much for joining me, Dr. Yeow.

Dr. Yeow - Thank you for having me.

Dr. Burchill - So I wanted to start pretty simple. What is palliative care?

Dr. Yeow - Yeah, thank you for that question. I know there's always been a little bit of confusion over the term, but palliative care really is specialized medical care that focuses on providing relief from pain and other symptoms for patients who are facing a serious illness or a life limiting illness. It is delivered by an interdisciplinary team of professionals that includes physicians, advanced practice providers, nurses, social workers, chaplains, and other trained specialists to focus on both physical and non-physical symptoms. Palliative care uses a whole person approach, as we acknowledge that living with a serious illness affects not only the physical but also the emotional and the spiritual aspects of life. And our team works with patients, their families, and the patient's primary physician or team to add that extra layer of support that really complements their ongoing care. Our team also helps patients and families navigate complex decision making and also clarifying goals of care as well.

Dr. Burchill - I mean, it sounds great, and a lot of people out there listening today are going to be community cardiologists. And so I'm going to sort of just dig a bit deeper on this first question and ask it in a slightly different way. If I were a community cardiologist, what's the advantage of engaging with palliative care? How does that support our practice?

Dr. Yeow - Sure, and I think, you know, for the community cardiologists out there, if you have patients who have sort of adult congenital heart disease and also with advanced heart failure, we know that their time might be limited. Granted, we don't have a crystal ball and none of us, you know, ever really are quite good at prognostication. But if you feel that your patient does have sort of a life limiting illness and has a lot of heavy symptom burden, and also has a lot of emotional or spiritual stress that's associated with living with a chronic illness, then our team can

definitely work alongside you as the primary cardiologist to provide that extra layer of support and also to help with some symptom management.

Dr. Burchill - You know, I know that we've been collaborating on patients' care here at Mayo Clinic. And my experience has been that there's a lot for me to get through in that visit when I see someone who's coming in with heart failure. And you know, sometimes I'm working on their breathlessness, their congestion. But also I'm trying to risk stratify. Sometimes we're talking about whether someone needs a defibrillator. There is a lot of ground to cover in that visit. And I have to admit, I think that often we don't have a lot of time for those other needs that you are talking about. So those spiritual needs, those emotional needs. Would you say that that's a key support that the palliative care team can provide?

Dr. Yeow - Yes, for sure. And I think one of the strengths of our palliative care team is the fact that we are an interdisciplinary team, and that we know that not one person themselves can address all those different aspects of care. So we do rely heavily on our specialty trained chaplains, our specially trained social workers, to help tease out some of those sort of distresses of the patient. That could be spiritual, that could be emotional, and also it could be physical too. And we work together as a team to approach that and to sort of tailor a care plan for our patients.

Dr. Burchill - And is it fair to say, this is my belief anyway, we were not born knowing how to have these conversations, correct?

Dr. Yeow - Correct, I think talking about some of these subjects can be difficult, especially as physicians. I think we are trained very much to look at numbers, to look at the hard facts, to look at physical symptoms. And we sometimes forget that living with a serious illness also affects, you know, the whole person. It affects us emotionally, spiritually. And I don't think many of us received much training particularly in medical school as to how to approach those subjects.

Dr. Burchill - I completely agree. And that sort of brings me to the next question. You know, when I was a young doctor in training, palliative care to me meant sort of hospice care. I wonder if you can update us. Already you've given me enough information to demonstrate the field is much more than hospice care. But maybe if you could just say, how does palliative medicine differ from hospice care?

Dr. Yeow - Sure, and I think that is definitely a very common assumption that a lot of our patients and referring providers have, sort of conflating both hospice and palliative care. And while both sort of hospice and palliative care really emphasize whole person care and sort of aggressive symptom management, palliative care can be provided during any stage of a patient's illness, sort of from diagnosis on, and can be provided provided concurrently with disease directed treatments. I see hospice care as sort of a subset of palliative care where the focus really is on sort of aggressive symptom management, but it's at sort of closer to the end of life. And it's also at a point where the patient is no longer pursuing disease directed treatments.

Dr. Burchill - Okay. And so what can palliative care offer my patients?

Dr. Yeow - Sure. You know, particularly, Dr. Burchill, with your patients who are adult patients with congenital heart disease, they can present with many symptoms. It can include shortness of breath, fatigue, depressed mood. And all of these symptoms can really limit their function and also negatively impact their quality of life. In addition, I think your patients and their families have been living with the stress of a chronic illness, and they often face really complex treatment decisions as well. So using the interdisciplinary approach that we have talked about, sort of the palliative care team can really work with the patients and the families to tailor their care plan to sort of improve their quality of life by optimizing symptom management, providing that extra emotional and spiritual support, and also offering care techniques that can help improve one's sense of comfort and sense of wellbeing as well. I also feel that we can also help patients and families with advanced care planning, and also provide guidance and advice as they face complex medical decision making.

Dr. Burchill - I'm really glad that you raised that because we've been talking about these select patients that are coming in and we're talking about sometimes a high risk surgery. There are others that we're seeing that are being referred for transplant. And you and I have been talking about, is palliative care part of that conversation, or should we just be referring them to the surgeon or to the transplant team and having a yes-no discussion? Where does palliative care come into that whole sort of dialogue around whether to take a high risk intervention for the next phase of someone's life?

Dr. Yeow - Sure, and I think our team can be helpful with just sitting down with the patients and families, you know, assessing their understanding of sort of where they are in their disease trajectory, assessing sort of their understanding of the treatment options that have been offered to them. And then just going through what's important to them, you know, what are their goals, what are their wishes? And are these treatment options aligning with their goals and wishes? You know, we are not here to persuade the patients and families to choose one course or the other. I think our role really is to sit down with them, tease through any sort of difficult decisions, and help them as they make their decisions that's gonna be right for them as an individual.

Dr. Burchill - Mhm, yes. Well, again, our experience with a couple of our patients, I can only feed back to you, Dr. Yeow, it's just been so helpful having your team as part of that conversation for really teasing out a better understanding of the dynamics for the patient at home in their community. Trying to tie that back to this often a big decision that's being made around an intervention. And also that conversation around, but what happens after the intervention? What happens if it's successful? What happens if it's not successful?

Dr. Yeow - Yes, I agree completely. I think some of what we do is also talking about the what ifs, the what if scenarios just so that patients and families can think about these issues in a time when it's not an emergency, rather than sort of having to face difficult decisions in a more urgent situation. You know, I think the other important thing too is writing down and documenting these discussions. And with some patients it's writing things down in an advance directive or a

living will. But that really gives their family some guidance and it also gives their medical providers some guidance as well in the event that they have complications from the procedures or the procedures don't go as well as we hope.

Dr. Burchill - And I know there was some research conducted by colleagues in Toronto some years ago now about the timing of these discussions. And what was really interesting is they contrasted the patient's preferences versus the clinicians. The clinicians often preferred to have these discussions when someone was, let's say, more unwell, or even unstable, or when there was some sort of imminent threat to the patient's life and wellbeing. Whereas the patients clearly wanted to be having these discussions sooner, even in an outpatient setting, maybe at a clinic visit where there wasn't anything particularly wrong, but it was the right time and space for them to think ahead to the future and what their care preferences might be. Would you agree that that earlier discussion is the one that we should be having rather than the late midnight hour intervention?

Dr. Yeow - Yeah, I agree. And you know, I know it's a difficult discussion and it's very individual to each individual patient and family. But I think given the choice, most patients and families do see the advantage in talking about these difficult what if scenarios when things are not an emergency, where they have time, you know, to ponder over these questions and to talk with loved ones about these issues as well. But you know, we always want to respect our patients too. And so we do give them a choice as to whether they want to go forth with conversations like these.

Dr. Burchill - Well, that's so helpful and I think a a positive note to end on. I agree, respecting patient choices is key. You've given us a lot to think about. The key points for me are we are not born knowing how to have these conversations. We also don't have to feel that we're doing it alone. There are palliative care specialists that we can call upon. And for patients and families that feel ready to have that conversation, your team is there. And you bring to the table a really holistic approach that's not just focused on the medical and importantly on, say, symptom management, but also a person's cultural, spiritual, emotional and other needs.

Dr. Yeow - Yeah, thank you.

Dr. Burchill - Well, thank you for your time. It's been great having this conversation.

Dr. Yeow - Thank you so much for having me.