Session 5 Full Webinar

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**SUMMARY KEYWORDS**

patient, people, questions, conversation, aaron, illness, substitute decision maker, life, palliative care, important, understanding, advanced care planning, trajectory, session, prognosis, talk, phrases, family, home, minutes

**SPEAKERS**

Hsien

**Hsien** 00:04

Oh, okay, I have 1202. So let's get started. If you have just joined welcome, we're going to start session five right now. And of course, you can complete the survey monkey in parallel or, you know, maybe after the session if you haven't had time. Today is a continuation about communicating with patients and families about serious illness. So it's part two, we went halfway through part one. The other session. Again, we're going to be hearing from the speakers Dr. Leah Steinberg, and Dr. Aaron Gallagher, who we heard some of which is questionable, oh, we heard some of their videos from before. And I hope you can watch them again, on palliative care innovation.com slash capacity if you missed last session, or, you know, people catching up. Neither them or I have conflicts of interest. This is funded by ci HR. And there's no financial disclosures either. So we're on Step five, halfway there, which is exciting. I know, this year has been quite unusual. So we didn't know how, what halfway would look like. But this is what it looks like. So we're halfway there. And sessions four and five are really critical about this discussion piece. And I think it's a skill that everyone can have not just, you know, clinician doctors or nurses, but everyone on the team can can benefit from these from these tips. So what I'd like to do is just spend two minutes we try to have a reflection, I know I just asked you to do a survey monkey by reflection, but if you were able to watch the video and do the 30 Day Challenge, it would be great just to refresh yourself. So I'll give maybe a minute or two to answer one of these three questions. If you either were able to look at the cheat sheet, if you were able to watch session four, sorry, the do the 30 Day Challenge, which was the video and if you were not able to do it, that's okay to maybe type in the chat box, you know, your plan to to watch it. The whole video series goals of care module calm is everything is there, I think for it might take, you know, a couple hours to go through the whole thing from top to bottom. And it's, it's very well done. We just asked for the 30 day challenge to just do Mr. Young's which is about 10 minutes. So again, just sort of as a check in for us and refreshing for yourself. in the chat bot cat box, perhaps. Let us know answer one of these three questions. Okay, well, I'm can also see the Maggie m. i.

03:14

Yeah, there's no comments in the chat. Okay.

03:16

Oh, twin Virgina says he has somewhat unrealistic expectations for his future. That's right.

**Hsien** 03:25

Okay, well, it's, um, so I know when, you know, we're not a chatbox group. But we, you know, we're taking a lot of online learning classes, and we're learning, you know, engaging with with the audience is important. And this is one of the ways there was something someone said something about security reasons. So my suggestion to that person is potentially to use a different browser, sometimes different browsers have different issues. But okay, well, the we made we actually have, you know, well, today's is about talking about evidence and tools. So we're going to continue with the framework, again, focusing on very practical tips and strategies, things that you could walk away with and phrases, strategies that you can implement right away. And for about 30 minutes of the session, we actually have Dr. Aaron Gallagher, who will be live here to answer questions. So again, I will ask people to put questions in the chat box. But if we're not that kind of group, maybe we will try having people mute and unmute themselves. But if you know, we have 80 people, and it'll be hard to have people all talk over each other. So that's why I think the chat box is one of the good, good options for us. So we can sort of moderate that. And we had Jocelyn, talk about the importance of silence. Yes, yeah. It's even as a moderator for these sessions, I have to practice silence So so so we'll have good practice and half of the session at 1230. So one of the things I want to flag for you now is get your questions ready. That's the lesson is there. Think about the questions about having a conversation. Anything you have will be Hear live, and she's already listening in, or anything that we've talked about from the beginning about capacity about early palliative care. That will be a great back and forth dialogue. Okay, so let's get started. Again, that's without the benefit of video, Dr. Gallagher is joining us. And that's Dr. Steinberg. If you remember this framework, we talked about preparing yourself exploring elements understanding the last session. And so today in the framework, we're going to be doing the rest of it. So we'll finish the whole framework. And today is really focusing on providing illness education, once you understand that, once you have assess their understanding what is the education you may want to provide or inquire if they want to provide. So I'm going to turn it over to Kayla now to put in a very short video, it's five minutes. And you know, a couple of good nuggets there. And then hopefully, we'll we'll have a brief discussion after

06:02

moving on to the next piece, it could be that after you've listened to illness, understanding that there are actually some knowledge gaps to fill in. And I think that that's often the case, even with very good illness understanding, there's often more information. But if somebody really, really doesn't know, I worked with many patients, say with chronic diseases like heart failure, who really don't know much about their illness, and what the trajectory is going to be like, there may be a big opportunity here for some illness education. The first thing to do though, is to always ask because I haven't used

06:43

it yet. I better not.

06:45

Give it to them at this point and to wait. So would it be okay, are you you've explained a lot about your heart, I'm wondering if it would be okay, I happen to know that there's a little more information that you might find helpful, would it be okay to talk about that today. The rest of the phrases here are things that I think everybody knows, but be very careful, we tend to talk in medical jargon all the time. Speak really slowly. But more importantly, if you're going to say something heavy pause after you've said it to see if it's actually gone in. So give a nice pause after something like your that the last time you were in the hospital, your heart was so weak, I was actually worried that that you may not have recovered. And then pause there and let that sink in and see what somebody responds. Same thing with checking for understanding, a mistake a lot of people make as they they use quality of life and suffering as if it's more about them than about the patient. So it's I find it rarely helpful to say something like, Well, I'm not sure your mother has a good quality of life now, or your mother seems to be suffering to me, it's better to ask the person about that. And then lastly, when you're giving information, try to use as many visuals as possible. And one of the things that I like to do is, especially for diseases like heart failure is to actually draw the up and down trajectory for somebody and walk them through what that looks like. And that gives you a way to say things like, you've had a few episodes where you were really sick, and you draw, you know, the graph going down, but you were able to recover. And one of the things that I think it's important to talk about is in the future, you may end up sick again. And at some point, we won't be able to fix that anymore. And then pause there and you can be drawing this with the trajectory. And I find it's a good way to introduce sort of values and goals and ideas about if they've ever thought about the future. Now people sometimes talk about prognosis, sometimes patients ask, but I think we also have this feeling like we're supposed to, you know, be able to give a prognosis. And the fact is, we all were terrible at prognosticating. But remember, prognosis is two things. It's the trajectory of the illness and the timing. And when we don't know about timing, we we still know often about the trajectory. And so I think it's reasonable, very reasonable to talk to people about what you expect to happen over time. Timing is something that sometimes we can give people some estimates about. And other times it's it's really difficult. So I think that's less of the the concern then than actually just talking about the trajectory.

09:33

being familiar with serious illness trajectories is extremely important when you are treating patients with life limiting illnesses because it helps first and foremost with illness understanding it is impossible to have a serious conversation with the patient if they don't actually understand the illness itself and the trajectory that it is likely to undergo over time. So these are three of the main trajectories. issues that we deal with with chronic progressive illness. First one being cancer, where a patient tends to be fairly stable after diagnosis, especially with some treatments that can help prevent progression of the cancer sometimes even cure the cancer. But it keeps it at bay only for so long. And then when there are no more disease modifying treatments available, you see a pretty steep curve coming off into the time of death. Things like frailty, decline is a little bit more slow all through the trajectory. So it started poor in the first place, and it continues on until the time of death. And then one of the ones that's probably the most difficult for patients to understand is the ones around organ failures. So like congestive heart failure and chronic lung disease were similar to frailty, you have a steady decline, but it is fragmented with these exacerbations that bring people's function down to a much lower level, and then they are rescued back up to a better baseline. But unfortunately, that baseline just doesn't meet the one that it was that prior. And so that's where you see that steady decline come in. I draw these out for patients, I find that you know, a lot of aha moments come when they see this on paper.

11:27

Now, once you feel like,

**Hsien** 11:36

okay, so quick five minutes there, and just wanted to give ourselves a minute here to just digest some of the things that we heard, because that's really some of the pieces about providing illness education. So I tried to put some summaries here of some of the key things, and we have this poll, because I know you guys love the chat box. So we're trying a poll here, which tip would you consider? So this is great. So it's, it's been about 30 seconds, I have about 55 of 82 people voting. So hey, the chat, this poll is working. We're pool people, not chat people. All right. Maybe I'll leave it for 15 more seconds, and 75% of people voted. And I'll tell you the responses in just a second. Okay, so we've had 80% of people voted, Oak share results, can I share the results, I'll just press share results, see what happens. So you can see about 42% would say they would try drawing the illness trajectory next time to have this, asking about their sense of suffering, as opposed to saying someone is suffering, saying, hey, what is your sense of suffering of your loved 120 percent might try that most of you would 63% would say, hey, would it be okay, if I shared more information about what the future might hold? So that's great. That's a asking permission before you offer the education. And then this idea of the prognosis, the timing versus the illness trajectory, you know, 17% of you would try it. Okay, well, these are all things you might try differently over time. And as an experiment, I'm glad to see that the polling works. so fantastic. So there was something people could take away. Great. So we're moving from the framework? If I'm not mistaken, let me check this out. Yes. Okay. So we can talk more about this with Aaron about the drawing the trajectory, but the other piece that didn't, you know, we didn't have as much as you draw the trajectory, but potentially the difference between where they think they're at on this picture, and where you think they might be at and allowing that to be an opportunity for discussion. And, of course, repeating this over time, so they, you know, might if things change, and what are the implications of that as a gateway to, you know, open up different discussions, if there's a change, or maybe things are stable, and, you know, that's also an opportunity for, for keeping stable. Okay. We're going to move to the next section of the framework, which is, once you provided some wellness education, how do we explore their goals and values and what's important to them, so some very practical tips about that. And I think this is also a four minute video or something like that. So I'll pass it over to kill it. To kick that off.

15:04

Now, once you feel like there's a reasonably good illness understanding, it's time to ask a bit about the values and you're going to use these values to guide you when you then make some plans or some treatment recommendations. I tend to like these questions. When you think about the future, again, the word question that when that one gets me a long way, other people ask things like, if time were limited, what would be some important things for you to do? Given what we've talked about? How can I help you going forward? What's most important for us to work on? So these are questions, there's lots of different ways to ask about values. Sometimes you'll find that you need to guide people more they don't really know what you mean by, you know, what's important, like, are you talking about, you know, doing my will? Or is it important that, you know, I can get a taxi home today, like, it's sometimes people aren't, aren't while obviously, they're not doing this work all the time. Patients, this is the first time they're going through this. So sometimes I'd like to guide them a little bit more, and I'll give them a little prompts with things like I've taken care of many patients with this illness, some of them and then sort of fill in the blank find it most, some of them find that the most important things are being able to live as many days and weeks as the doctors can provide. While others aren't quite as worried about the number of days, they're more worried about how they're going to end and how their family is going to cope. So I kind of usually put out a range for people so that they can be on the same page, what I'm talking about. Now, since we're asking people for their goals, something that people often ask me about or worry about is, well, what if they say things like, well, I want to be cured, or my goal is to get back to work? When you know that that's not realistic? How do we support someone when they actually when they want what we can't do? And the fact is, I think it's much better to acknowledge and explore that goal. And the three W's is the trick that I use here is really a trick, but it is the, you know, the tool that I use here, I wish I worry, I wonder, I wish, I really wish that I or the oncologist had treatment that I felt would work well enough that you could get back to work. I worried that that might not be the case. And I wonder if you and your wife have ever really thought about what what might happen if we can't. So I find that's a nice tool to use. I've already talked about not pushing medical facts on emotions or resistance.

17:47

And then lastly, you now have something.

**Hsien** 17:58

Okay, so the idea of providing some illness, education, but then now allowing the opportunity to talk about what's important to them how all that information affects they themselves, the patient and the family, and what all that means for them. And so, similarly, we have some neighbors, several options of things you might say or ways you might talk about that or open the door to allow them to talk about what's important to them. And so we have another pool. Okay, well, maybe leave it open for another 20 seconds or so. Okay, I think we reached about the exact same number last time. So there might be some people on phone who it's it's hard for them to vote so I'm gonna should share the results. So you can see I think it's being shared. The when you think about the future, is there anything that worries you That was the most popular potential phrase that you may use with 41%? The I wish, I worry, I wish you you know that she'll feel great for another couple years. I worry that may not be the case. And I wonder if you know what is important to you that kind of And then if time were limited, what would some important things be for you to do? Not so popular was the last one about more time and less time. I also think one thing that I've heard too is the idea of Are you the kind of person who likes to do a lot of planning and look in the future? Or are you the kind of person who likes the day to day, because sometimes the patient likes to stay in the day to day, but the family caregiver is the person who's planning. And so they might have different answers or different things that they want to talk to you about. So that's another conversation to have, okay, I'm going to stop sharing these results. And I appreciate that people are filling out the survey, and we're gonna keep moving on. So again, I hope one of the things that we're learning is opening the door to these conversations is not, you know, something that's extreme, it doesn't always have to be very complicated, it can be very simple, right turn of phrase, can just open the door, and invite people to the conversation and make, you know, suddenly make things a lot easier, or at least, you know, create, create the opportunity to to go forward. And introduce palliative care, the ideas, the the philosophy of palliative care earlier, as opposed to the idea that people are just not wanting this right now. So the last piece of this is creating a plan. So now that you've done these, you know, these three blocks in the middle, the orange, blue, and purple, how do we go forward making a plan? Okay, so Kayla can take over and sure this is a shorter video, it's just a couple minutes.

21:41

You've got some ideas about what they value, and what they're hoping for. And it's time to make a plan. And that plan may be as simple as Let's meet again, and keep talking. Maybe you only got as far as starting an illness, understanding conversation. And that's all anybody had time for. And so you're going to say, look, let's do this again, in a couple of weeks. When you're doing work around advanced care planning with people, this is where it'll differ than if you're having a goals of care conversation. If you're doing advanced care planning. Your plan may look like, you know, want you Mrs. Smith, take this booklet home, from the state of speakup campaign and work on this with your husband, who's your substitute decision maker, and then come on back and we can talk again. Or it may be you've just introduced the topic, and they've said, Oh, I don't know anything about it, is there something I can read and you can say, Yep, take this home and come back and we can meet again, that may be all you do with advanced care planning. It could be that they come back with a completed form. And what you really know it's not a form, like the treatments, but a form that explores their values. And your plan may be let's bring your husband in next time and go over this together. If you're having more of a goals of care conversation, then your recommendation will be more your plan will be more of a recommendation. And so the skills I like to use here are, first of all, always ask, you can say, you know, you've given me a lot of information, would it be okay, if I gave you a recommendation based on what you've told me. And once they say Go ahead, then then they're ready to hear it. Then relate your recommendation to the goals. So it sounds like it's really important that we help you talk to your children. That sounds like a good goal. We can do that. Let's choose a time for them to come in. And we can talk together. And then finally, always ask for feedback because you could you could get it wrong. And then you can say, you know, what do you think sometimes if I'm having sort of more of a conversation about resuscitation and sort of very specific treatments, I might make a recommendation and then somebody will say, Oh, no, that's not what I understood. And so we it just means we have to go back and kind of take another go at it. Another example is so you feel strongly about your independence and avoiding further hospital trips. I wonder if we might talk together with your son to help him understand this. What do you think so that would be more around sort of advanced care planning recommendations. Think about the language you use, we tend to use really negative language when we're making a recommendation. Let's stop the fluids. Let's stop the antibiotics. Let's not do any more tests. instead try to use the caring what we're going to do language the positive language first. We will use medications to help your mother feel comfortable. We will use oxygen if that helps her with her comfort and nursing care to make sure she's clean and well cared for what I wouldn't recommend that we do and then sort of go into the negatives so that's the kind of force March quick through the The steps of these conversations with a couple of examples. The main principles are to remember to explore with your patient. Search for more meaning by asking why push pause on your agenda or wanting a specific outcome. And to realize that these are often iterative, there are ongoing and recurrent discussions. There's rarely an urge, urgency. The main goal in mind is to understand your patient and offer support and guidance and then recommendations. So lastly, the take home messages are, take the best of the different guides and the education modules and don't do it all in one visit. Focus on illness understanding, let the patient lead involve family and caregivers, especially around advanced care planning. advanced care planning is only as good as the substitute decision makers agreement. Don't give information to emotion and definitely don't start with your agenda. And then,

26:06

okay,

**Hsien** 26:09

so we talked about making a plan some tips there, and then the wrap up of the whole piece. So if I'm not mistaken. We have our last poll besides the one at the very, very end. So our last little poll, which I'm seeing people are filling out. So this is good was in this sort of creative plan. Were there any phrases looking at these things, or any of the tips that you found? most helpful? So let's pop it up? Okay, it's, I'll leave it open for another 1520 seconds. And if you're not able to see the poll, you can always Oh, I guess put it in the chat, which it's the one of these bullets on the side. Okay, let's close the poll. And I can share the results here. So the top one was let the patient lead the discussion, learn what the patient's think. Illness understanding, focusing on that first and taking the time it needs was next most popular and, you know, knowing that it might be several conversations. My favorite rule is don't give emotion information to emotion, but because I always, I see that a lot with, with, with patients and caregivers who, who are avoiding the conversation because of the emotion, emotional impact. But that's exactly what Leah said in an earlier session, there's what we need to lean into. That's where we can dealing facing the emotion is how well then we can talk about information. Okay. So I, this is the so these are the steps. I think I have to close this poll. Good. And now we can open it up for discussion. So we How about we try using the chat box first. So as I sort of introduce Aaron, which we did it before. Aaron, you can unmute yourself. And thank you so much for joining us. I don't know if you want to turn on your camera, you're absolutely Welcome to if you're not in a place, that's easy to do that Not to worry, while maybe while people are maybe putting in some questions in the chat box, and then Maggie can let us know. And if that doesn't work, people can unmute themselves. But let's try the chat bot first, just because there's 85 of us on the call right now. So if you have a question to put in the chat box and Maggie will will, will be the first but the Aaron did I don't know you watch those videos. What was your sense? Like? Do you have any sort of messages that really resonated for you? These are all you know, they're you're well aware, these are all primary care teams across the province who are trying to introduce the idea of early palliative care earlier. And obviously, they're the super early adopters, because not only were they the first to sign up in the province, but also during covid. They're still excited to come back. So we really have the most eager group here. So I'm looking forward to the questions. But what were your sense of the videos and any tips you have?

29:33

Yeah, my, my first impression was, oh my gosh, there's 87 people on this call. That's so cool. So yeah, kudos to every single one of you for coming out and joining this discussion and for the great work that the organizers are doing. I did I took a couple of notes, just as the first sort of half hour went on. Jocelyn had made that great comment about how powerful silences And letting people form their own conclusions. So I know when I go into a home, and I'm doing a consult on a patient meeting them for the first time, they'll start by telling me how things are going. And one of my, you know, bang for buck questions is so you know, and usually in in the context of deterioration, I'll be able to ask them, so, you know, what do you think is going on? And people will often give me a very insightful, well thought out answer that actually takes away a ton of work from me having to explain what's going on, it's a really good way to to see where they're at, and to meet them where they're at, and where I need to take over if there are some gaps there and their understanding. So I agree, I think I think silence and bringing it back to the patient to give that explanation initially is, is very, very helpful and powerful. And I could go on, but I, I just want to make sure that there aren't other questions, because that's the priority.

**Hsien** 31:07

For sure. Okay, so maybe, maybe I'll turn over to Maggie. Maggie, you're watching that.

31:11

Yeah. So I so Aaron, I sent you a question before from Jenna, about thinking about planning and involving the family in advancing dementia. So I wonder if you could speak a little bit about if a patient has a different care plan idea from that of their family? How do you bring it all together? Especially if the patient is changing their plan, often related to the disease?

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Yeah, I mean, that. The short answer is, I don't have an answer for you. There are, you know, some factors there that we just have to follow, right? medical legally, and that is just accepting always that as long as the patient is capable of making their own decisions. That's what they do. That is why it is so important when a patient is still capable, to choose who is going to make those decisions for them when they can no longer do it. Because if it's the son who's not agreeing with you, or the brother that is not agreeing with you, that should not be the substitute decision maker or the power of attorney, if the substitute decision maker is who you don't want it to be. So very much around following those basic principles. in family medicine, I'm a I'm a family physician, as well. So I do treat families regularly and run into these issues quite often. And I think a huge portion of this is information sharing around what it actually means to progress into end stage dementia. Because some people know they've had experience with loved ones, and they get it and others don't. They think that they're going to live at home alone until the day that they die. And you know, they're very stoic about it, and they don't want any support. And so these are conversations that take a lot of time, a lot of tinkering. But always emphasizing the patient's wishes, and making sure that the right person is in the lineup to help support those decisions when the time comes.

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Great. Thanks, Aaron. So we have another question from Brian about if you could speak to what happens when a patient has fear about their inheritance issues.

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Patient fears about their inheritance.

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Like around their, their estate and their finances. Is that the question?

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So Brian, I'm gonna ask you to come off mute maybe and expand a little bit.

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If you can't hear me, oh, yeah,

33:44

no, we can hear you. Yeah, good.

33:45

Yeah. Okay, so we're the patient has fears about the family fighting over their inheritance. Yeah, it's a great fear. And I can speak to it from, from that point of view, and also from after it's all happened, where some of the errors are, are talking about the battles that are going on since since they lost their loved one.

34:06

Yeah. So, you know, this is, this is a big part of really needing to have those conversations as early as you can. You know, it came up earlier that one of the really great questions I think it was that Leah said is, you know, what are your fears for the future? Right. And it is such a great question, because this is how stuff like this comes up. Right? It's, it's people give you answers, like, you know, I don't want to die in pain, or I don't want to die like my sister, but you also get things like, I'm afraid my children are never going to talk to each other again, because of the inheritance or I don't know what's gonna happen to my pet snake. Right? Like there's so many different things that people will come out to like with when you ask just something as broad as that. What are you afraid of? If we can ask those questions earlier, we can get a head start on supporting them. I mean, obviously, legal advice is helpful, but not everybody can afford that. Right. Usually there is some counseling available to people. Again, if we activate it earlier, you know, we can counsel patients around that because we, with more practice and these amazing skills that you guys are picking up can pick up on people's values and what's important to them. And those things can guide financial decisions as well, not just healthcare decisions, so we can help with that too. But yeah, there are legal resources, Counselor resources, system navigators out there that can certainly help with that. One of the things also, that we need to be honest about, and I talked to my learners about this a lot, is that people typically die the way that they've lived. So if they have lived a chaotic life, with not a lot of organization, lots of ups and downs, lots of turmoil, lots of trauma, chances are, it's not going to be a smooth ending, it doesn't mean that there isn't a ton that we can do to accompany that patient through their journey and make it the best it possibly can. But in the end of life for a patient when their family is suffering, around knowing that their loved one is going to die, and you are suffering, because you know that you are going to leave your family, people don't turn to their positive coping mechanisms. So these things do get worse, right? battles that have been maybe up until now just sort of floating under the surface can really accentuate. And so really just being frank and open and honest about that, you know, at the end of the day, you have to pay attention to what you can control. Because this is this is your death. This is your money. I know you love your children, and you want to do everything that you can for them, but you can't control, you know, what's been going on for the last, let's say, 40 years, right? So really focusing on what people can control would be another piece of advice that I would I would give to you. But similar to the last question, right? I don't I don't have a black and white answer to that. It really is about forming relationships and trying to get a good understanding about where first and foremost the patient is coming from and what they value, but also the family context.

37:36

Okay, great. Thanks, Aaron. So how would you handle situations with language barriers? So have you ever used a translation service or gone to another provider?

37:47

Yeah, it can be really important, I think about a patient of mine. It's the most challenging case I've ever had. Actually, it was a young woman with esophageal cancer, who came from a very small village in Pakistan. She spoke only Pashto, which is a very uncommon dialect for my understanding. And I could not find an interpreter for the life of me, even through their, their temples and various organizations, I looked far and wide, and I couldn't find it. Unfortunately, what it resulted in was massive medication errors. Unfortunately, there was a single family member who took the brunt of all of the care. And she barely spoke English as well. And of course, the the one who spoke the most, and the best language was the one that lived the furthest away. You know, it's so classic in our context, but it is so important to do if you can find an interpreter. There are also lots of different cultural beliefs and nuances that can be misinterpreted, and forced on a patient that aren't necessarily, you know, consistent with their beliefs if you're not able to communicate with them directly. Most hospital systems have access to a service. Many large family health teams have access to a service they differ throughout the province or throughout the province and our throat regions. But yeah, I think it's I think it's a very important thing to pursue, if you can. I don't have a list of resources for you today, though.

39:31

Thanks, Aaron. So another thing that Catherine has asked you to comment on is a situation that she's faced where there's a reluctance to share information with the patient who is ill or at the end of life. So for example, if friends or family members have died, there seems to be some kind of something I can't read that word on behalf of the family members. So the Fed members don't want to share information with the patient. So do you have any thoughts on on that?

39:57

Yeah, I've been there too.

40:00

And it's really hard.

40:04

There are situations that are more straightforward. And you know, whether it be a cultural belief or just a general belief that the family can make the decisions for me as the patient, or that having too much information about prognosis will take my hope away, and I will give up, and I will no longer fight. And I will get depressed. I mean, there's lots of different versions of that, depending on who you ask. And I think that there are ways of having those conversations with a patient where you can accurately get their consent to continue those conversations with family members, where the biggest dilemma lies, and you know, again, I can give you another example, we had a very aggressive surgeon in our area, willing to do a surgery for a patient of mine, who, whose family spoke for them made decisions for them, you know, we had navigated up until that time, but like, the survival rate of the surgery was like 5%. And if they survive, they would probably spend the remainder of their life in hospital, which was completely inconsistent with the great conversations we had about values and what was important to them. So like, to me, that was a huge ethical dilemma. And what I did was I reached out to mentors, I reached out to people who, you know, could help me navigate this, whether it be you know, other palliative care physicians, you know, psychosocial spiritual advisors, people who work specifically in ethics. I mean, these are the people that you want to surround yourself with in a time like this. Because you know, at the end of the day, by going against the patient's wish, even feeling though you're doing the right thing, it can drastically reduce the trust that the patient and the family has in you. And that doesn't benefit anybody, right? At the end of the day, you're all sort of way back from where you started. So you have to proceed with caution in those circumstances. So all that to say, I think it can be done well, and it can be done very carefully in in respecting the family's wishes with the patient's consent. But there will be challenging times that, you know, again, there's no black and white answer. But if you can surround yourself with really good people, and really good resources, it'll give you more confidence in proceeding.

42:45

Hey, thanks, Aaron. So a question from Kelly is about what if there's many STM so of children who do not agree with the plan for their loved one?

42:55

As I'll keep this one short, because I think I would just be reiterating what I said before, and that is have these discussions early. Many people don't know that there is such a thing as a substitute decision maker list that has been created by the government. Right? So you know, for those people out there that hate how much the government controls their life, well, here's another, you know, here's another example of how that happens. And so even just letting patients know that that exists, is very empowering, because often they'll look at that list and go, Oh, hell, no, you know, it's not going to be so and so. So you need to have those conversations early. You need to make sure it's the right person. And I always encourage people to have a single substitute decision maker, it doesn't mean that those people can't talk together, right? If you have a family that has, you know, for the most part, got on well, they're all you know, sort of reaching the same conclusions based on what their loved one is telling them of course, because at the end of the day, that is what matters, then we only really need one person to communicate that but they can always have the support of the team that's been supporting their loved one all along.

44:15

Thanks. So I think that's all the questions that I see in the chat. So I don't know if anybody wanted to come off mute. And oh, I just got another one here. From Heidi, if you could clarify the government list of f of stms and how that is created if the families are unaware

44:30

Yeah, so you can you can google it to be honest it's it's everywhere. But there is a power of attorney kit through the Governor General's office I believe that you can print off and it goes through a pra for for personal health and for property and I pretty sure it outlines the SDM hierarchy, but if not, like I said, you just need to make sure that speak up another one. Perfect example. Yeah, another great resource. Yeah. Thanks, guys.

45:05

Yeah, I don't know if anyone else wants to come off mute and ask their question to Aaron directly, we still have a few more minutes. So feel free.

**Hsien** 45:13

So Karen just asked, How do you deal with made? So I don't? That's kind of a pretty broad question. I'm not sure. What Oh, maybe maybe I think she's asking is what if you want to introduce early part of Karen, someone is asking about made? How do you how do you? What is your response? I guess?

45:28

Yeah. Karen, have you got like, Is there an? Is there a scenario that you've been in that you would like, be comfortable elaborating on that, that could guide my response to that question, because it could be? Oh, my gosh, it could be a whole seminar series.

45:50

You bring that up, then how do you deal with it? How do

45:55

I start? So you were broken up a little bit there when somebody brings it up? How do I deal with it? Yes. Yeah. Okay.

46:03

So and you know, what, it comes up a lot

46:06

these days, and part of me is wondered if COVID is playing a role in that actually, and the isolation that many of our elderly and sicker people are feeling. So that's an aside. But when people ask about made, there are two reasons. One is because they are suffering in some way. And the other reason is that they anticipate suffering in some way. Okay, so that's how I break it down. Sure, there's lots of different ways. And so the most important thing is to one, acknowledge that you heard it. And then to seek clarification, you know, thank you for feeling comfortable bringing that up with me. Because, you know, for a lot of people, that's a really contentious topic. But I personally am very comfortable going there with you. And I would love to learn more about what's making you think about this. Right? So it's always about discovery first, no matter what, and you will learn a ton about a patient, if they have the words to describe why it is that they're thinking about this, right. And it can be because they knew somebody who had the procedure, and they really agreed with, you know what happened, and it went really well. And then, you know, you can explore that further, there's tons of information in exploring the depths of other people that your patient knows, because whether they be good or bad, they can very significantly influence what their anticipated experiences of their own death. So yeah, better understanding. And then I probably, I mean, I wouldn't do it all in one visit, unless I only had the one visit. But if I had permission to give them more information about it, I would probably refer them to a resource. And that's, again, through government websites, where they discuss what made it is and you know, what the first steps would be and what the process is, and you know, the 10 day waiting period and things like that. I usually talk about what we had before made, and that was, you know, palliative sedation, right, something that we could use. If we had to, you know, I always say in the rare event that we can't get on top of people's symptoms, we could have always used palliative sedation. Right. And, and that's still on the table. Right? So, but again, it's rare, and you know, at the end of the day comfort, right? We we tend to give this the spectrum to people about what we're going to offer them, you know, make me live longer Do everything you can comfort only right on the other side, and it's kind of like well, conference non negotiable, right? Like that's going to be something that I'm going to probably try my best to accomplish with you all along, no matter where you are here. Right. So again, talking more about palliative care as well, and and what can be offered and I like to emphasize the size of our toolbox. Because if people just don't know, right, they don't know how many tools we have to treat physical and emotional symptoms as people approach the end of their life. And that is so reassuring to people because if you can come in with confidence, which I think courses like this will contribute to for you to be able to walk into a room and feel confident in what you can provide and to feel confident that if you don't know the answer, you know where to go to find it is huge.

49:51

Thanks, Aaron. So another question is about how would you respond if a patient or caregiver responds to your conversation starters and says, I don't know And then a long silence. So is there a way that you would recommend that this could be explored? Like, have you ever put a pause on and come back the next visit?

50:11

So you're, I mean, this is a patient that, you know, is just it's like pulling teeth, trying to get stuff out of them is that's what I'm getting from this question. Yeah. Okay. Mmm

50:28

hmm.

50:33

It's such a good question. And, you know, it's definitely not one that I'm prepared to answer today. Reading the room always plays a really big part in how I pursue these types of people. I think, first and foremost, are they ready to have me here today? Right? Like, are they in pain? Are they uncomfortable? Did something recently bad just happen? You know, did they get an update in their prognosis yesterday, like, you know, maybe it's just today, right? It may not, it might not be a forever thing. And it's just about sort of slowly building up some trust with someone, and, you know, maybe trying to find some more neutral ground. So for example, if I am in a patient's home, which is like it's so it's so enlightening to go into people's homes, because I can talk about their dog that hasn't left my ankles alone, or like just the really bizarre artwork on the wall, or, you know, there's so many things that you can try and pick away at people with. And then as you practice those things, then there are what's the word? It's like, it's like a crack in the wall, right? You know, you might actually, you might be able to see a point of entry there with a patient to dig a little bit deeper, starting benign. And then as long as you are looking for the cracks, you can probably find your way there with time. But it would probably require some follow up with a patient like that. And then, you know, Leah had some great advice, too, right. So the more conversations that you've had like this, the more examples you'll have of what other people would have said. So you can always go back to those two. You know, if you're saying, you know, what are your fears, you know, there's lots of really great literature out there on what people fear as they're approaching end of life. And so you know, you can read an article like that. And it might actually give you some good ends around what people might be fearing and get the conversation started.

**Hsien** 52:52

And I'm just checked doing a quick time tickets, we have about six minutes before it ends. So what I maybe want to do is give you the last word, I know you said you had some notes that you feel like you wanted to leave any parting words for all our, our practitioners, I suspect, some of them, you know, are still trying to figure out how to I don't know how often they go to the pay patients homes. I'm not sure. But that was one of the barriers just the whole time thing like if, you know, how much time does this take to do it? Well in the Senate, but that was put in my question, but but I want to give you the chance to have the last word I don't know if that ties into just just higher level than just these conversations, just the whole idea of, of getting over the hump of, of trying and doing and the idea of earlier palliative care as opposed to palliative care being about end of life.

53:40

Yeah.

53:42

Yeah, so no, I don't have any great like epiphanies or words of wisdom written down. I do love that you brought up the idea of home visits and things like that, because I do think that us going into the community is how we can help our patients the most. In their last year of life, it's about 5% of time that patients are spending with us. 5%. Right. And that's probably an over exaggeration, in their final year of life. And that's with, like people who provide services, right? Doctors, nurses, social workers, but the other 95% of the time they're at home. Right and and that's where their quality of life is defined. And so if we can't immerse ourselves in that, I think we're not we're not giving them the best care that we can. And so I'm definitely a huge, huge advocate for that, and have pursued that work because it's probably the most rewarding. You know, I work in a big family health team setting. There's about 18 docks where I work and there is another 18 docks at our sister clinic and You know, we're at we're teaching unit right here at McMaster. And so I think there's always this conception that we do things very well. But that's, that's definitely not always the case. You know, I get requests from my colleagues all the time, saying, you know, my resident really hasn't had exposure to palliative care, you know, can you hook them up with, you know, maybe one of your patient visits coming up or a palliative care elective?

55:28

I'm going to have to take a really deep breath.

55:32

And think that like, we all know that about 1% of our patients die every year in our practices, right? So there's got to be, you know, like 12 people in an average practice in a year, who are in their last year of life. Some of them are very unexpected. But there's so much opportunity just to use that surprise question. Right? Who would I be? Who would I not be surprised if they died in a year? And then you go back right to the things that Leah was talking about? What is their illness understanding start there? Right? You would be shocked. You might even you probably already know how many people that have had COPD or CHF three years, I can't tell you what it is at all. They really they don't even know. They just know they're on puffers, right. Something showed up on the X ray. And they're on puffers. So, you know, even just starting their early identification, using that surprise question, tackling illness understanding, asking them what they worry about in the future, and starting advanced care planning. I mean, it's not, it's not rocket science.

**Hsien** 56:39

Yeah. I really appreciate you taking the time. And I hope people enjoyed the conversation. I'm going to wrap up in our last few minutes. So we've gone through this framework here, which I you know, in today, we did a lot of polling of some questions and, and phrases you might use. So we obviously want to have these conversations earlier, you know, multiple conversations over time, knowing that you don't have the answers, but, and framing them as things. What is it saying giving? Oh, it's about the patient's agenda and giving them a sense of control. Okay, this is some of the things about the practical tips that you can learn. And so our 30 day challenge is to try to try this out, test it out on a few patients, see how you feel. And again, you prepare yourself and just start with almost understanding and just see where that leads you. And I think in a prior session, we talked about, you know, potentially, you know, putting these patients at the end of the day or at the beginning, so that you you know, you have more time with them. I think in the last minute, we just want to do our, our one minute evaluation poll of how you found today's session, and and then send you on your way. So if Kayla can help me do that. Okay, so as that polling is ending, I'm just going to just thank you very much. Hope you have a good month. Again, there's a cheat sheet about this that you can download. This webinar will be put online on palliative care innovation, comm slash capacity, email, myself or any of your the team Maggie, Kayla Daryl, if you have any questions, and again that in 30 days, you'll get a survey from us to let us know how this was. So keep safe everyone and and try it out. Just try these little phrases and see where it leads you. I think you'll see it's a whole new world when you invite patients in the conversation. Many patients and families want to have this conversation and want to share that with you and help and have you be their coach and guide through that. So So take care. We'll see you soon. We'll see you in a month.

59:49

I told it to started at one o'clock.

59:54

That's crazy.

59:56

Thank you

**Hsien** 1:00:02

For the person who just joined at one, maybe in the next day or two, this one hour will be posted online. How that of care innovation.com slash capacity so you'll be able to watch it then. Oh,

1:00:13

thank you.

1:00:14

Yes.