When should people get palliative care?

Palliative care is specialized medical care focused on relieving the symptoms and stress of a serious illness and improving quality of life, in alignment with a patient's individual goals, values, and priorities. Although palliative care consultation is recommended for millions of Americans with serious illnesses, many patients aren't referred to palliative care or only receive a consultation at the end of life. Evidence shows that early palliative care consultation could help many patients with chronic serious illnesses better understand their diagnosis and align their treatment choices to their individual care goals.

The largest-ever study of palliative care led by researchers Dr. Scott Halpern and Dr. Katherine Courtright of University of Pennsylvania demonstrates that a default palliative care consultation is an effective strategy to give more hospitalized patients the opportunity to benefit from palliative care sooner. We are talking to the researchers to understand who should get specialized palliative care, when they should get it, what does "early" really mean and what is the impact the recent study will have on palliative care.

Full Transcript:

Priya Menon: Hello and welcome to CureTalks. This is Priya Menon your host. Today on CureTalks, we're discussing Palliative Care, more specifically when should people get Palliative Care. We have with us pulmonary and critical care physician, researcher and director of the PAIR Center of the University of Pennsylvania, Dr. Scott Halpern. PAIR actually stands for the Palliative and Advanced Illness Research Centre. Joining Dr. Halpern on the panel is Dr. Katherine Courtright pulmonary and critical care and palliative care physician researcher who is also a core faculty member at the PAIR Center at the University of Pennsylvania. Patient Advocate joining the panel is Jeremy Pivor. Jeremy advocates for brain tumor and is a patient ambassador on palliative care for the EndWell Foundation. Welcome to CureTalks everyone.

Dr. Katherine Courtright: Thank you.

Dr. Scott Halpern: Thanks for having us.

Priya Menon: Dr. Courtright, my first question is to you. It's very basic but a very significant one so that we can set context for our listeners and also as a main focus of our discussion today. When should people get Palliative Care and when is the best time that is during treatment that you should start looking for or consider Palliative Care?

Dr. Katherine Courtright: Yeah, that is a great question. It's an easy and complicated answer. So, the easy answer is, the earlier the better. Once someone's diagnosed with a serious illness much of the research and certainly the field has really advocated for earlier Palliative Care. Some of that's based in really excellent research particularly in oncology patients, a really landmark study among patients with non small cell lung cancer, but that's been extrapolated, further and some more observational and patient reported work has supported earlier being better. The challenge and the complication is what does 'early' mean and I think we're going to get into this with some hopefully with some other questions, but certainly the field would really struggle to see all patients when diagnosed with serious illness at that time and really keep up with basically the volume of that, and so how do we sort of both provide earlier palliative care but also high value in terms of when, and I think it's going to end up that we both need more research to answer that at a disease level. Maybe it's not the same for every disease state and likely it's not but I don't think we know exactly yet the precise, and there's no one time that somebody's serious illness that they absolutely need or should. It's really about when your needs are in Palliative Care that you should get it.

Priya Menon: So, this eligibility of you should get it or it's better to start early, is this determined by a clinician referral or diagnosis?

Dr. Katherine Courtright: Yeah, so in general, it's determined by the clinician caring for you. You would have to recognize that this may be something you benefit from and then suggested and make that referral. I think folks have seen the challenges of that and how that leads to perhaps inequitable and late palliative care where the benefits are more limited that you're getting it really towards the end of life when you could have had value and benefit to you and your family earlier in the disease course, and so that's where other ideas come in such as basing it on a diagnosis or basing it on a prognosis and maybe Palliative Care needs screening to sort of systematize and not have clinicians be the only gatekeeper if you will to somebody receiving palliative care when they could benefit from it.

Priya Menon: So, it's been like I've had a very personal experience, like my mother was recently diagnosed with interstitial lung disease, right. And it's been a year. She's stable now on steroids. But we have not been like nothing about Palliative Care has yet been mentioned to us. And you said starting early is good, right? So, I really wonder should this be something that we suggest to the doctors or clinicians, or do we just wait and see, because she can manage on her own by now. She's not using any or she doesn't need any intervention other than steroid medications?

Dr. Katherine Courtright: That's an excellent question. I will always say that patients and family should advocate for palliative care. I think that, as I just shared clinicians unintentionally are gatekeepers to this kind of care they do either don't know about it, don't think about it at the right times, have misperceptions about it, all the reasons like are busy or thinking about for example steroids how to make your mom feel better, the tools they have and are sort of this might not be the first thing on their mind. And so the more we can make patients and families understand how it could benefit them and that it is not only end of life care and it does not need to be a scary word, the more likely you are to receive it even if not at the time, let's say you bring it up next time with the pulmonologist and they say, well I'm not so sure and you have that conversation . What you've done is plant a great seed in that pulmonologist's mind such that if and when you see your mom has more symptoms or something else is contributing to a lower quality of her life, that will be more on their mind than it will be on your mind and you're more likely to get it earlier than you might have other.

Priya Menon: Thank you.

Dr. Scott Halpern: Priya, just to add that there's a saying that I think captures a lot to your question, which is Palliative Care always feels too early until its suddenly too late. And one of the challenges is helping people feel okay that there's nothing bad about too early.

Priya Menon: Absolutely. No, yeah, that's one of the reasons why, when this topic came up and I was discussing it with Maha and your study came up, I was like really excited because we have talked about palliative care before on CureTalks. We have talked about palliative care for cancer patients. And your study was which says that you have default palliative care, right? So, I was very excited to read it. So, Dr. Halpern, maybe you can just briefly talk about what the study is, and I really want to know what made you think of doing this study?

Dr. Scott Halpern: So, early in my career, I got interested in the idea of nudges or the field of Behavioral economics, which basically changes contextual factors in the way choices are made such that, choices that we want to have made are more likely to be made but we're not removing any options from the choosers, and we're not materially altering their incentives to make one choice or another; we're just setting up the choice in a way that makes a desired behavior more likely than it would otherwise be. And extrapolating from that sort of basic social science interests to clinical medicine revealed a whole host of ways we make decisions, in ways that could be improved upon. And the way we get Palliative care and other specialist teams involved in our patient's care is one of those. We knew back in 2005, 2010 that there were never going to be enough specialists trained palliative care clinicians to see all the potential patients who would benefit from them. But we also knew that we could make the palliative care workforce go further, that there were tiny proportions of people who should be getting palliative care who actually were.And so, the first motivation for this study when we thought of it back around 2011 was how can we make the thing we want to have happen – seriously ill patients who are more likely than not to die of their disease in the not too distant future to start receiving palliative care.

The second motivation was we didn’t have a lot of what I would call super high-quality evidence of what the benefits of palliative care really were in an objective sense. We had a lot of studies that took observational designs. So, comparing people who happen to get palliative care to people who happen not to and drawing conclusions from those, somewhat happen stance comparisons. But of course, the highest level of evidence in medicine comes from experiments, randomly assigning people to get one thing or another. And we didn’t have a lot of that at the time. So, it struck me that we couldn’t ethically, we knew enough about palliative care being a good thing already, but we couldn’t ethically randomize, Jeremy, you’re going to get palliative care and Priya you’re not, that just wouldn’t be ethical and it certainly wouldn’t be appropriate. But we could randomize in a way that the likelihood of an order for palliative care for Jeremy is higher than the likelihood of an order for you, Priya while your respective clinicians can still make a choice one way or the other. And so that struck us as a way to enhance the rigor of the evidence base around the effectiveness of palliative care. So those are really the two motivations.

Priya Menon: That’s nice. That’s really interesting. The other couple of words, technical words that I’ve heard about being discussed about this talk and I think you have explained this on many other podcasts but I would really request you to explain this in very layman’s language for our folks here. One term is the pragmatic trial, or what is a pragmatic trial because even we work with clinical trials, as part of our company actually works on try trials and matching trials to patients. So, this pragmatic trial is again a new term for us. The second thing, that the trial is actually described as a pragmatic stepped wedge cluster randomized trial. I mean, like I know it took me a few minutes actually to read it and understand and what is a stepped wedge design, right the entire trial is unique and the number of people that you have been able to, your sample numbers as well as design of the trial. So, can you talk a little bit about that and elaborate a bit?

Dr. Scott Halpern: Yeah, so, all clinical trials exist on a continuum, and one way to name that continuum is on the one hand you’ve got what we call explanatory trials and on the other pragmatic. And you can think about the differences between the two along the lines of the **who, what, when, where, why and how.** So, the why is really the key like, why are we doing an explanatory or traditional trial is usually to ask the question, can this treatment work under optimal conditions? Whereas a pragmatic trial tries to ask the question – does this treatment work under real world conditions? And if you think about those cornerstones of the sort of why we are doing the trial. The who and where and what kind of follows suit. In pragmatic trial we want a very generalized population, usually a large sample where we include everyone who could potentially receive that treatment. And we typically conduct it in real world settings. So, we don’t have a lot of research coordinators doing things. We have regular clinical staff doing what they would normally be doing with certain interventions layered on top. We collect data from electronic health records and other existing data sources. We don’t do a lot of additional study related data acquisition. So, all those things make a trial more pragmatic.

Typically, pragmatic trials will be larger. Typically, they will be more real world. And typically, they’ll be more applicable to settings outside of those in which they were conducted. That’s not to say that we should have all pragmatic trials, we need both, but this was a decidedly pragmatic. In terms **of the stepped wedge design, this** comes down to how we go about random assignment. So you can randomly assign patients. So, in the example I gave earlier I randomly assigned Jeremy and Priya, I could randomly assign Hospital A versus Hospital B versus Hospital C and we call that cluster randomized design, the hospital in this case being the cluster. And the stepped wedge cluster randomized design is just a variant of that where instead of taking in this case 11 hospitals and randomly assigning about half of them to have the default palliative care intervention and about half to not. We randomly assign the time at which each of the 11 hospitals transitions from not having the intervention to adopting the intervention. So, all 11 hospitals, ultimately get it in this stepped wedge design whereas in a what we would call a parallel cluster design only half of them would have ever gotten it. And frankly when I started shopping this idea around the Health Systems, around 2011,

2012. I couldn’t get any hospitals to sign up if we had proposed to randomly assign half not to get the intervention because all the health systems were saying we need to do something. The status quo is not okay. So, this was a design that was made in large part or chosen in large part for practical reasons and in response to the needs of key stakeholders.

Priya Menon: Interesting, very interesting. I’m just going to hand over to Jeremy now, so that he can ask his questions. Jeremy, all yours.

Jeremy Pivor: Thanks Priya. And thanks, Dr. Halpern and Dr. Courtright for the research you’re doing. It’s incredibly important, and very passionate about Palliative care and I think everyone needs it or should have the choice to have it. I was reading about your article and my first question is for Dr. Halpern, you mentioned when you were talking that Palliative care is not end of life care all the time. So, how do you address the stigma though that is associated with Palliative care and often the misunderstanding that Palliative care does equate to hospice care both for doctors and also for patients?

Dr. Scott Halpern: I’ll start briefly but I’ll also ask Kate to weigh in here as our rep. Kate is a true palliative care clinician unlike myself. So, will have a little bit more experience. I do think it’s important to recognize that Hospice Care is often provided by people who are trained in the broader discipline of palliative care. But is a specific and very small subset of the paliative care landscape and arguably is even a distinct entity unto itself. So, Hospice Care is comfort focused care at the end of life, and the key distinction while palliative care also seeks to promote comfort, it seeks to do a lot of additional things. And the key distinction is it’s good at any time during the course of a serious illness journey. One need not be near the end of life to benefit from palliative care. Whereas one for sure needs to be at the end of life even to qualify for hospice care. Messaging is key here as far as stigma goes, as it always is and I know Kate has a lot of experience introducing herself to families and probably addressing this question head on.

Dr. Katherine Courtright: Yeah, I echo everything that Scott has said and as Scott said there’s sort of sayings in the field one of the other ones, is that all of hospice care is palliative care, but not all palliative care is hospice care. So, like I said there they are interrelated and a lot of the tenants remain the same, and in the goals of what we’re trying to relieve in terms of the distress and symptoms of living with a serious illness. But hospice is focusing on dying well with a serious illness and living as well as you can for as long as you can. Whereas palliative care is really focused on also mitigating the stress and symptoms of living with a serious illness for you and your family, but you can be receiving curative therapy while receiving palliative care and that to me is one of the key distinction is that word cure. A living longer can be your goal, getting cured as can be your therapy goal and you can benefit from palliative care.

Messaging wise I do think the field and research and advocacy and getting it out in the lay public, as we had talked about having patients and families ask for it, actually educates their clinicians and so that’s sort of mutual education and then the other piece is going into the rooms and describing what you do when you go in and say hi I’m Dr. Courtright from the palliative care team, I work with a social worker and a psychologist and a chaplain and a nurse to help you with symptoms, stress, support your family through this illness, and whatever’s going on in your journey right now. Nobody said leave, and they don’t turn you away. So, a lot of it is how we talk about it, and if we can have our referring clinicians use similar language, it’s a lot less scary.

Jeremy Pivor: Thanks for that. And so I was reading about your study and I saw that you chose hospitals that all had palliative care teams, and I was wondering how do you scale this approach at places without palliative care teams? And how do we train more health care providers in palliative care recognizing that we’re not going to have enough palliative care specialist to cover the entire country?

Dr. Katherine Courtright: Okay, so that’s a great question. We have the same one and I think that long and short this is challenging. I’m as a researcher I wish we could answer all the questions in one study and particularly for how much work and how long they take to do but the reality is we cannot and so a lot of our ongoing and sort of developing research is actually getting right at that core question. Stemming in part from the findings of this study like default order worked, we increased consultation more patients got palliative care, and some end of life care processes were improved and yet many who had that order accepted were not seen. So, how do we it can't just be train and hire a bunch of more specialists. They don't exist. There's a pipeline problem and we can work on that and there are pathways trying to increase specialists, but it'll never meet all the needs. And so how can we have our referring clinicians and every other clinician of all stripes and healthcare has the ability to address symptoms and distress of serious illness in the routine course of care. And so, we're very fortunate that many folks have dedicated their careers to developing palliative care education for precisely this reason. So there are expert, both courses, intensive courses for clinician training, there are web-based ones, there are short, few days intensive courses for communication training.

There is absolute access to get this kind of education that honestly, we did not get in medical school. Certainly, when I was getting training and I think that's getting better but a whole generation or more of a clinicians are missing this training, and yet it's fundamental to caring for patients full stop. So, I think health systems are investing. They just don't know where to put that investment in what kind of training, they don't know what to promote and the best way to determine that is with evidence, what works and what are clinicians willing to engage in, what's easiest for them and yet high value and changes outcomes in groups outcomes.

Jeremy Pivor: Yeah, thanks for that and I completely agree with everything you just said. In the article I was reading about Palliative care article, there was a sentence quote that even in the intervention group, less than half of the patient actually received a consultation from a Palliative care specialist, and so I'm wondering first why? Also how could this be changed? And how do you prevent a default order from being potentially ignored or making sure palliative care is prioritised?

Dr. Scott Halpern: I can take a stab at that. So, you're right about, 45-47% of people in the intervention group where palliative care was ordered by default actually received at least one or more consults. And that actually was about what we expected, and the reason we expected that was not because we imagined that the default order would be ignored, and in fact, it wasn't, and we didn't even imagine that the default order would be opted out from or canceled very often and indeed it wasn't. Only about 9% of the time did the bedside clinician say, Okay, I see what you're doing here; you're ordering palliative care for my patient, I don't think that's appropriate. 9% is not zero, but it's not a lot. It certainly doesn't get us from 100% down to 45%. So, the big bulk of the difference is explained by the issue we went off with which is that I think you can make a credible argument that specialty trained palliative care clinicians are the scarcest of all healthcare resources. There simply aren't enough, and we knew that no matter how strong or effective the default, we weren't going to get all of the patients in our denominator palliative care. We accepted that as an okay limitation because we also knew that without doing anything the proportion of people who were getting palliative care was like 15%, like a third of what we wound up with. So, if we can triple palliative care rates and have them start on average more than a day earlier,. I think we can feel pretty good that we're doing something right.

Jeremy Pivor: Yeah. I think so too. Besides, go-ahead Dr. Courtright.

Dr. Katherine Courtright: That's okay. I was just gonna add that, I think it speaks to opportunity, both for training generalists sort of non-specialists as we just talked about clinicians, like look all of these folks may benefit from kind of care weren't able to get it because of say resource constraints in the field, that doesn't mean we shouldn't do something. So that's an argument that there's an opportunity there to improve palliative care delivery one way or another, either by say clinicians being trained or more specialists. The other opportunity which we learned and again are employing in some of our newer trials is to better select our population. So, it's really challenging to – who is likely to benefit is not highly defined, well-defined or empirically defined. So, we're really chipping away at that question. But what we think is that sort of just a sort of crude cut across diagnosis while we went with advanced serious illness, it was just based on diagnosis. And there are other ways to hone in on maybe you have a serious illness diagnosis and a prognosis that is limited, maybe you have known Palliative care needs and a serious illness diagnosis; and how we can combine these things to sort of better target who right now with your intervention is most in need and likely to benefit might then better target that limited resource, as Scott said to the people most likely to that effect. I think we just need to keep chipping away at that question – The Who?

Jeremy Pivor: Yeah, thanks for that. And my last question, I read that the primary outcome of the paper was hospital length of stay. How could you include more value-based metrics into your research on palliative care? As for me, that's what I advocate for was really for patients to really define what they value in terms of how they want to live their best life, and then doctors be able to help guide them towards that?

Dr. Scott Halpern: We probably can't begin to tell you how many times we've had this exact conversation, and this is a classic story of we made a decision that at the time seemed for sure like the right one and even looking back, the reasons behind that choice do make sense. But in retrospect, it just looks like a bad choice nonetheless. So, let me unpack that a bit. At the time that the study was designed, the entire business case of palliative care was predicated on the assumption that it reduced the length of stay. Why was that business case needed? Because we live in a country with a warped reimbursement structure such that clinicians and hospitals get paid to do procedures, not to spend time talking to people. And so, palliative care doesn't bring in a lot of revenue. So, the entire field growing was dependent on some alternative business model to justify its existence to health systems in order for them to invest in it. And that was predicated on reductions in the length of stay. If you reduce the length of stay in a world with high demand for hospital beds, you then have more people cycling through each bed on an annual basis, and that brings in more revenue for the hospital.

So, if you can do that, even though the field itself, even though like Dr. Courtright is not getting paid a lot to do a palliative care consult, her hospital might get paid a lot if she's reducing the length of stays and that was the business case. And we had to know if that was true. In addition, I would maybe push back just a little about the value proposition. I actually think that a reduction in length of stay is a good thing for all stakeholders. It's good for the hospitals as I just explained. But I've never met a patient who wanted a longer length of stay rather than a shorter one. I've never met a family member who wanted their loved one to not come home as soon as it was safe to do so. And I've never met a clinician who wanted to keep their patients bound to a hospital bed rather than get them back to their daily lives. So, I actually do think it resonates on a value scale for all stakeholders. And yet nonetheless, I will never ever design another trial with a reduction in length of stay as the primary outcome because it's just really hard to move the needle. There's too many factors that influence it to imagine that a single intervention in this case to all palliative care was going to make a huge difference.

Jeremy Pivor: Priya, before I hand it back to you, I'm curious, Dr. Courtright your perspective on how you conclude more or other metrics that you could measure in future palliative care studies based on your experience working with patients.

Dr. Katherine Courtright: Sure. I'd like to think we're getting smarter about this and being a little bit more flexible in our own thinking, so as Scott shared earlier this trial was highly pragmatic, everything sort of ticked the box for what a pragmatic trial should really be, including that the data was collected routinely in clinical care. And as you may know we don't routinely in clinical care systematically ask patients and families how they're feeling in 1 month or 6 months after they're discharged and get all of those responses, that would be lovely. And so, I think what we're doing now is making better efforts to incorporate pragmatic outcomes and that are collected during routine care and really broadening the scope of those so that we can tell what I like to say, a whole story at the end of the trial. We do actually have to pick a primary outcome as Scott suggested, that's the way it works. And that's how we designed the study from making sure it's rigorous and we have the power to detect the differences we set out to do but we can also measure many many other secondary outcomes of the processes of good serious illness care of good end of life care, and then importantly we're really starting to get savvier about and reaching out to patients and families in our trials after and the hospital stay and querying their quality of life, their experience with the hospital care and kind of care specifically communication and other such metrics that patients and families tell us are important.

Those are limited because you certainly have people who can't or don't respond but I think we can keep pushing the envelope on that again just to try to tell a more complete story at the end of a big trial like this. And then the last peice i will add is that we are also doing better than we necessarily did in this first big trial is qualitative work where we’re reaching out to clinicians who received the intervention, make the referrals, we’re reaching out to the Palliative care clinicians to patients and families sitting down and having interviews with them where we start to unpack more of the things that we can’t necessarily quantitatively measure, but again would fill out some of the hypotheses we have at the end of the day, we have all this quantitative data and then we have to sort of make interpretations and hypotheses around why it looks like it does and that qualitative work that information coming in from those stakeholders, can really inform those. So, I think those pieces all coming together will help us tell more of a complete story with each of the limitations of those data collections.

Jeremy Pivor: Yeah, thank you both. Really appreciate the work that you are doing in new other patients, really appreciate advances in palliative care. So, thank you. Over to you, Priya.

Priya Menon: Thanks Jeremy. In the interest of time, I’m just going to wrap up with the last question. I want both of you to weigh in on this, just to discuss the significance of clinical research teams in providing day-to-day support for patient-driven research.

Dr. Scott Halpern: I think it’s a great question, Priya. The entire model of the PAIR Center is predicated on the notion that it takes a village. And it really does to pull off any rigorous study. It takes a team where faculty research coordinators, statisticians, data managers, project managers and the list goes on and on, all have equal, complementary and defined roles to play. No one persons’ got all the requisite skill sets and it’s why at the PAIR Center where we have about 60 people only 10 of those people are faculty and more than 40 of those people are highly trained, highly accomplished research staff who are aligned with our mission and they bring incredible value day in and day out in their specific areas of excellence, operations, timeline adherence, patient accrual, setting up the data sets in ways that make sense, applying the most advanced statistical tools to evaluate those data and the list goes on. And ensuring that human subjects rights are protected. That’s a key piece, too. And it is just foolhardy in my view to imagine that any one or even two people could do all of that themselves and have the end product be something you’d be proud of.

Priya Menon: Thank you.

Dr. Katherine Courtright: I think it’s not at all an exaggeration to say that I would not only be doing this work, but I would not honestly have a job if it weren’t for our clinical research staff. It certainly wouldn’t be fun. The team based environment is absolutely part of this work, and the foundation of it and why we come to work every day. And I will reflect on that, often because I think what I’ve realized is everything we do in medicine that is better with a team. ICUs are designed around teams because of the complimentary, and work and expertise we all bring to provide better patient care. I just shared that palliative care is incredibly a diverse interdisciplinary team and absolutely provides better care because of that and so I think clinical research should be no different. It should really reflect the clinical care we provide which is interdisciplinary and multidisciplinary.

Priya Menon: Thank you. Thank you, Katherine. So, I really want to discuss more about what PAIR Center is doing and some more details, maybe in another show, but definitely would like to discuss this on CureTalks again. In the interest of time, I’m just going to wrap up today’s session. Doctors Halpern and Courtright and Jeremy, thank you for this is very informative session. We also thank University of Pennsylvania, and this talk will be made available on curetalks.com and Penns pages. Thank you everyone and have a great day.