

“Past, present and future opportunities in palliative care research”

Dr. McPherson: Hello, this is Dr. Lynn McPherson and welcome to palliative care chat, the podcast brought to you by the online master of science and graduate certificate program at the University of Maryland.

I'm very excited that we have two guests today. What a action packed value production we have for you here today. Our first guest is Dr Jennifer Tjia, who is an associate professor of medicine at the University of Massachusetts Medical School. Her research interests include health services, research, and pharmacoepidemiology. I'm always telling doctor Tjia that I really like her research because it's so darn practical and her research really focuses on optimizing the use of chronic prescription medication by older adults, particularly in nursing home residents with advanced dementia and near the end of life.

Our second guest, who's really a rock star in the field of research and palliative care, is Dr. Sean Morrison, Icahn School of Medicine at Mount Sinai. He is the director of National Palliative Care Research Center and he will be talking about the history of palliative care research with us. Dr. Morrison is the Ellen and Howard C. Katz professor and chair for the Brookdale Department of Geriatrics and Palliative Medicine at Mount Sinai. He's also the director of the Lillian and Benjamin Hertzberg Palliative Care Institute and the NTC RC. They're both organizations devoted to improving care for persons with serious illness and their families, and enhancing the knowledge base of Palliative care in the US.

So I could go on and on for 20 minutes but welcome Dr. Morrison and welcome Dr. Tjia. So nice to have you with us today.

Dr. Morrison: Thank you.

Dr. Tjia: Thank you [inaudible 00:01:34]

Dr. McPherson: So I am always telling anybody who will listen how fortunate I feel to have been born when I was born because when I started my career hospice was, oh I dunno, about eight or so years old in the United States and palliative care really was still just finding its legs. It's only been a board specialty for physicians since I think about 2006 so I've been able to witness the birth and the development of hospice and palliative care. Of course I am very, very, very envious of people who are 30 years old because they get to see the next 40 or 50 years.

So given that palliative care in particular is such a young field, I thought this would be a really good topic to talk about. How did we get off the ground moving research forward? So Dr. Morrison, perhaps we can start with you to address this lack of evidence in this brand new field you've pursued this area of

research and palliative care. So being at the forefront of this effort, can you paint a picture of the landscape of palliative care research, perhaps historically where we've been, where we are, and where do you think we're gonna go from here?

Dr. Morrison: Yeah, so I think if we go back and trace really the beginnings of the modern palliative care movement it really starts in the mid 1990s when the support trial was published, which demonstrated that there was rather an intolerable amount of untreated symptoms, unmet goals of care, and poor care care coordination in our nation's hospital.

And at the same time that support was published there was also the beginning of the assisted suicide movement and Jack Kevorkian, which I think made many of us in academic medicine sit up and say, "Wow, the public would prefer to speak with Dr. Kevorkian in the back of a VW Bus than think experience living with a serious illness in the nation's hospitals."

And at that time hospice existed as a superb model for caring for people at the very end of life in the last six months and many in academic medicine thought, why not take the best that hospice has to offer and apply it to those living with serious illness, those living with serious illness of all ages, and indeed those who are living with serious illness and might expect to be cured. And so with very little evidence base, but a good idea, the modern field of palliative care started. And I think it became very apparent very quickly that we lacked an appropriate evidence base to deliver the quality of care that patients and families deserve, that we had very little evidence that would allow us to treat distressing symptoms other than pain.

Dr. McPherson: Mm-hmm. I just-

Dr. Morrison: That we .. Sorry.

Dr. McPherson: I'm sorry. No, you go ahead, please.

Dr. Morrison: That we understood that a key part of caring for somebody with serious illness was the ability to communicate serious news, engage in goals of care discussions, understand patient's values and how they met, or in how our treatments could meet those values, and how to make difficult decisions near the end of life. And there was absolutely no evidence base that allowed us to understand how those decisions were made or how to teach them.

And then the third gap, which I think we all recognized pretty quickly, was that we had a model of care that was hospice that was a community based model of palliative care for people at the end of life but we really had no care delivery models that would provide the added layer of support that people with serious illness needed who were not in hospice, who were, for example, getting curative treatments such as a bone marrow transplant, who were gonna live for

many, many years with a serious illness or, for example, happened to be under the age of 21 and were children in which there was no evidence at all.

So I think those were the ... It was the clinical need, it was the lack of appropriate care models, and I think it was the struggles around communication that really jump started research in this area.

Dr. McPherson: It just seems to me that the whole idea of palliative care must have struck such a chord among practitioners that they had an Aha moment that this is why I went to medical school, nursing, pharmacy, social work, whatever. It just seems like it went whoosh and we all jumped into clinical practice. And when you compare the growth of palliative care with the field of internal medicine, which is 3000 years old, I find it amazing. So are you saying that A, do you agree with that and B, but we jumped in with both feet before we started to really do some research?

Dr. Morrison: I think that's true. I think that the need was so pressing and so evident that many of us, as you said, had tapped back into why we went into medicine. It was really about caring for the person and more importantly caring for the person in the family and that made sense from a clinical perspective.

The challenge from the research perspective is that the research infrastructure in the United States, and specifically the National Institutes of Health which fund the majority of nonpharmacological and non device research in this country, is set up in disease specific silos and that with the exception of the National Institute on Aging and the National Institute of Nursing Research, which are relatively modestly funded, the rest of NIH is set up to fund disease specific research. And that's a mismatch for palliative care research because palliative care research spans a number of different diseases and in fact many of our patients have several, and so that there has not been and there was not a good fit for the needs of the seriously ill and the need for palliative care researchers in the current infrastructure.

The second issue that faced us in research is that for most of modern medical research history the focus has been predominantly on finding the cure, understand the illness, and finding the treatment and that's based on the fact that if one can cure a disease, if one has an effective treatment then the suffering associated with that disease goes away and the problem vanishes. And what's left unspoken and often unsaid is what happens if that cure doesn't exist, that treatment is only partially effective, or there are multiple diseases and conditions all happening at once? And that's the case for the majority of our patients and families and yet we don't have research or we don't have funding that's going to address that.

Dr. McPherson: Mm-hmm. And for either of you, Dr. Tjia Or Dr. Morrison, it just seems that what we do in palliative care, for lack of a better term, is kinda touchy feely, it's

kind of a soft science. Doctor Tjia, you do a lot of qualitative research. Has that made it more difficult do you think for researchers to jump into this game?

Dr. Tjia:

I think the fact that it is more squishy or about people's feelings has really put challenges of how do you do communication research, or how do you measure people's feelings to encounters at the forefront. I think that palliative care has been very fortunate that thought leaders and researchers, like Karen Steinhauser, were right up there doing high quality qualitative research upfront to say, "This is how we define high quality death."

And yeah, it's probably made it more challenging, as Dr. Morrison suggested, because that type of research, at least I think 10, 20 years ago, was much harder for NIH to wrap their brain around and fund. I think that's sort of changing, but we're fortunate that folks such as Dr. Morrison and Dr Steinhauser sort of led the way in saying we need to change the research funding paradigm to make that happen.

Dr. McPherson:

Mm-hmm. So true. Any other challenges that either of you want to talk about in doing palliative care research, or have we covered the waterfront there?

Dr. Morrison:

I think there are several other challenges that we should talk about.

Dr. McPherson:

Okay.

Dr. Morrison:

The first is, and I wanna come back to your comment about squishy research or touchy feely research. I think that comes ... those labels come from the fact that the research questions in palliative care are really hard, and they're not straight forward, and that they are not narrowly defined as, for example, looking at a cell, or developing a drug, or developing a molecule that is very, very specific.

And so there is a tendency to sort of dismiss what I would call complex or hard science as squishy, or poorly defined rather than real science. And I think when you ask patients and families what's important to them you don't get simple answers, you get complex answers. So that leads me to what are challenges?

The first is that the patient population is very complex and that traditional research models, traditional research designs, and traditional statistical analytic methods are not well matched to a complex patient population. We like things that are very narrowly defined, very straight forward, and in some ways very easy to answer, the classic randomized controlled trial. And so number one is the patients are complex.

Number two is that it's only recently that we have been able to think about research design and analytic methods that match to the population at need. Pragmatic clinical trials, for example, is one approach that we started to think about rather than the traditional RCT. Hierarchical growth modeling, weight and class analysis, these types of statistical methods that recognize heterogeneous

complex populations which have just become developed. Propensity score matching to address bias in observational studies, instrumental variables all have developed within the past 10 to 15 years. And we need again, a better evidence base into the analytic methods we're facing.

And then number three, I think the big challenge facing us as researchers is that not only is it a complex population, but it's a very, very sick population and because of that respondent burden becomes a huge issue. How do you deal with missing data becomes a huge issue. Proxy respondents, dyadic research because it's rarely just the patient but the patient and the family and these are all research challenges that most people in biomedical research are not facing yet are absolutely critical to overcome if we're going to improve care for this most vulnerable population of patients and families.

Dr. McPherson: Oh, as you were speaking I was thinking of my IRB application process and talking about vulnerable populations and I was like, oh my gosh, that's everybody that I ... that's everything I do. It's difficult, I think.

Dr. Morrison: Yeah. Yeah.

Dr. McPherson: Very much so. So Dr Morrison you're the director of the National Palliative Care Research Center who has a mission to strengthen the evidence base foundation needed for health policy and clinical practice in palliative care medicine. So what was the rationale for starting NPCRC and why not just go to NIH for more money?

Dr. Morrison: Yeah, there were three specific reasons to start it and overwhelmingly obviously it was to fill a gap. So NPCRC was started with three goals in mind. The first was to create a new generation of palliative care researchers and enhance the workforce capacity, and that we've done through funding early stage investigators with career development awards to give them a leg up in terms of competing for NIH career development awards to give them an extra two years of time to develop as a researcher and to fund experienced investigators to do pilot or exploratory work, which would essentially serve as the pilot background significant section of an NIH grant. Again, to allow those folks to have a leg up in competing at NIH study sections where palliative care research was not being seen.

The second goal was to create a technical assistance program to help investigators through providing consultation on new analytic methods, pre reviewing grants before they were submitted in order to give people an extra review and advice. And with early stage investigators providing training on particularly on research methods, designs and analysis they may not have learned in their training programs.

And then the final goal was to create a national community of palliative care researchers because when NPCRC started back in 2006 there were very, very

few programs in the country that were large enough that could provide a home for palliative care researchers, and that most of us were working in isolation in nursing schools, and schools of medicine, schools of social work without a cohort or a tribe of similar researchers. And what NPCRC was developed to do was to create a virtual home for those researchers. And NIH is just not set up to do that. That's not what their mission is, that's not what they do, and that's not the type of community or that's not the center that they funded through their center program. So that's why NPCRC started.

Dr. McPherson: And Are you pleased with the success so far that you've accomplished?

Dr. Morrison: Yeah, I think we're very pleased with the success we've accomplished. Certainly when we look at hard numbers as to what NPCRC has accomplished overall for every dollar that we've spent, our investigators have garnered an additional \$15 federal funding. When you roll those numbers up, that's a bit over \$200 million in federal funding.

Dr. McPherson: Wow.

Dr. Morrison: We've seen the number of applicants every year skyrocket and most importantly applications are coming from a very broad spectrum of medical nursing schools and schools of social work where in the early years it was really coming from less than 10 schools.

Dr. McPherson: Mm-hmm. And pharmacy, don't forget.

Dr. Morrison: And pharmacy. Actually we have not been able to fund ... We have not had a pharmacist funded through our program, not for lack of trying.

Dr. McPherson: Oh well we're gonna have to work on that.

Dr. Morrison: So certainly both the numbers and the quality investigators we have have really grown since NPCRC started. And what's been very exciting is that as a result of a lot of the work that NPCR has done, and others, the American Academy of Hospice and Palliative Medicine is starting its own separate standalone research conference, which will be beginning in March of 2020 so that the field is now at a point where it can support a separate standalone research meeting-

Dr. McPherson: That's excellent.

Dr. Morrison: ... for science engaged in improving care for people with serious illness.

Dr. McPherson: That's wonderful. So for either of you, we've been talking about how research in palliative medicine can be about physical symptoms, it could be emotional, such as the perspective of the patient and family, spirituality for example. And I would agree that all this research is important, but what about health policy? Is

there a rationale for doing research in health policy? This is part of NPCRC is mission, I believe?

Dr. Morrison: There is, and just a clarifying question then I'll let Jennifer answer that one, when you say health policy, what exactly do you mean?

Dr. McPherson: I Think Dr. Tjia, this is something that you suggest we discuss. Can you elaborate perhaps?

Dr. Tjia: Well, I think that health policy, to my understanding, is when we have regulations or rules, either at the local but probably more at the state or the federal level, that really influenced either, let's say, quality metrics for what programs are expected to do, or can influence the payment models for if we can pay for palliative care at home per se. That might influence outcomes.

And I think health policy research is, in my understanding, is to see whether those types of interventions, that I think many people don't think about as research, it's not about the patient, it's not at the doctor patient level. It's really much more about the payer and the regulatory level. That's an area of research that I think is also super important and has been supported, at least my understanding is, by the NPCRC. But I'm curious to see what the thought is for that and where that's going.

Dr. Morrison: Yeah. I think what I would say is that in terms of true policy research, it's not something that we have engaged in. But that's very different from engaging in health policy, either advocacy, or operations. So for example, NPCRC and others are very active in improving NIH funding for palliative care research. There has been, we worked with a number of organizations to put into statutory language in 2019 that NIH and AHRQ needed a cross institutional strategy to promote palliative care research.

We've been very active in promoting and the Palliative Care and Hospice Education and Training Act, which creates both centers of excellence in palliative care research, but also directs funding for palliative care research at NIH. That passed by a voice vote in the house last year. Got a little bit, let's say it stumbled a little bit in the Senate because it was taken up too late in the year, but is now moving forward both in the house and the Senate in this year. And so that's an example of policy change related to research that we've been actively engaged in and working on.

Dr. McPherson: Great. So what's the role of industry sponsored research in palliative care, if any?

Dr. Morrison: There hasn't been a tremendous amount. The role of industry sponsored research in this country has typically been around drug and device. And for the most part, unfortunately, industry has not focused on development of medications focused on symptoms. And that has been a very, very big gap.

Dr. McPherson: Mm-hmm. It's difficult. I know so many of the medications we use are old medications and there's no one that really is gonna fund those studies. It's very challenging. So what would you both say are some of the major successes in Palliative care research? What do you think are the big wins?

Dr. Morrison: Jen, do you want to take that one? Do you want me to start?

Dr. Tjia: I'm curious to see what you would start, then I'll jump [crosstalk 00:23:35]

Dr. Morrison: Okay. I think there's a couple of big wins. I think that, excuse me, I think that the evaluation of both the quality and costs of hospital palliative care teams has led to dramatic spread in the prevalence of palliative care in American hospitals. When you just look at the almost linear growth that's occurred in the past 10 years because of data that has demonstrated both improved quality with reduced costs. So I think that's certainly a very, very strong bit of research. I think it's-

Dr. McPherson: Before you go on can I jump in there? And from the little bit that I understand about this, that's been kind of hard to do because a palliative care consult team not necessarily generates money but is more about other outcomes. Is that correct?

Dr. Morrison: It's more ... Well it's about the fact that when you treat patient's pain and other symptoms, align treatments with goals of care, and facilitate safe discharge planning and transitions you reduce hospital costs, and you reduce them fairly dramatically. You reduce unnecessary emergency department visits and 9-1-1 calls, and you allow for better utilization of hospital beds and ICU beds to different patient populations who are more appropriate for those beds. So I think that-

Dr. McPherson: And that's what makes the C suite happy, that kind of data. Correct?

Dr. Morrison: Mm-hmm. Well I think it makes everybody happy because we spend more on healthcare than any other country in the world by about a factor of 1.5. so if we can reduce costs in one area, we can improve care and put cost to a different area. So I think it's a win win for everybody.

I think the second major research finding that has really helped the field has been the demonstration that not only does palliative care allow people to feel better, not only does it reduce cost, but it's associated with increased longevity. And there have now been seven randomized controlled trials that have demonstrated that people receiving the added layer of support of palliative care in combination with traditional disease directed treatments live longer than those who don't. And I think that has been a key finding in palliative care. And that-

Dr. McPherson: That reminds me of Dr. Pantelet who's always saying if palliative care were a drug every doctor in the country would wanna write for it and every patient would want it.

Dr. Morrison: Exactly.

Dr. McPherson: So true.

Dr. Morrison: Exactly. And then I think the third big area where we've made huge strides is on understanding the science behind communication, and the recognition that we don't come out of the womb being born good communicators or not but that there is a scientific basis to communication, there's specific knowledge, a specific set of skills, that these can be taught, that they can be practiced, that they can be improved upon, and they can improve outcomes and I think that's been the other major innovative ... if I had to pick three research areas or research findings that have come from the field.

Dr. McPherson: And so many of the skills that are inherent in these three big wins that you've described, I agree with Dr. Vangunten's model of primary palliative care. Everybody should be able to do those three things. Would you agree?

Dr. Morrison: I think that everybody who practices medicine should have core palliative care knowledge and skills of pain and symptom management, good communication, and understand how to help coordinate a healthcare system for people. No, I would definitely agree that those are-

Dr. McPherson: Sure.

Dr. Morrison: That's just the fundamental parts of medicine.

Dr. McPherson: Absolutely. Dr. Tjia I know you and I share a common interest in doing a better job preparing informal caregivers, family members, to take care of their loved ones who have a serious illness. Can you speak to that a little bit, about why this is so darned important and that stress that we're putting on these people?

Dr. Tjia: Yeah, certainly. So I think that we ... I think Dr. Morrison mentioned this before is these folks are so sick that they're not going through any of the [inaudible 00:28:20] of their care that they're receiving in the hospital, or the care they're receiving at home, in hospice, or even in palliative care. They're doing it alone.

And I think the evidence is showing that it's really important to measure and monitor the effect that this is having on the family caregiver because it is adding to their stress, it does contribute to their own morbidity and mortality and illness, and that there is a need to actually help them take care of themselves, one ,to help them take care ... do the things that we are asking them to do. For example, if when folks get admitted to home hospice, how do they actually carry out all of the different tasks of administering the medications or

monitoring symptoms and this, as you say Doctor McPherson, for you and I has been an active area where we're looking at what do those family caregivers need, how do we understand that, how do we train our system so that we can meet that need, and how do we measure when we're doing better by them and right by them? So that's [crosstalk 00:29:27]

Dr. McPherson: Such an important area, goodness. So I guess one last two part question here. What are the challenges for palliative care research in the future? And part two of that is are we doing a good enough job preparing the researchers of tomorrow? What do you both think about that?

Dr. Morrison: So I think there are ... Let me start with the first one, question first. What are the challenges? I think there are really three. I think the overwhelming challenge is appropriate funding for palliative care research that without that the field is not going to move forward. And until we move NIH funding beyond the 0.1% that is now being directed towards improving care for people with serious illness, we will not move the needle on palliative care research or we will not move the needle on improving care for people with serious illness.

The second challenge that we need to address is the workforce, that we simply don't have enough people engaged in this area of research yet. Part of that is simply because it's a brand new field and we just haven't got the numbers, but we really need to think about how we're going to address that and what we're going to do to enhance the evidence base.

And then I think the third big challenge that is really facing us is that we've done a lot of work, for example, in cancer but we have not done nearly enough research in the other areas of serious illness that people are living with, particularly the combination of frailty, cognitive impairment, and multi morbidity. That combination of three syndromes that older adults are living with.

And I guess I'll add a fourth onto that, which is we need to focus on kids.

Dr. McPherson: Yeah.

Dr. Morrison: If you think the evidence base in adult medicine is small, it's intestinally small in people under the age of 21. so I think those are the three big research challenges we're facing.

Dr. McPherson: Mm-hmm. Dr. Tjia, anything you wanna add to that list?

Dr. Tjia: The only thing that I would also add to that is just the actual challenge of carrying out the research itself, and Dr. Morrison touched on this before, it's these folks are dying and they're very sick, and how do we do that trade off of enrolling them in studies, and asking for their time, and asking for them to answer questions if we're doing survey based or interview based research, or

how do we engage families at that critical time when they're really, their loved one is seriously ill? Just the whole challenge of actually executing. I think it's been there, we know a little bit, but I think there's more to learn about how to do that, and how do we do that with our partners.

Dr. McPherson: Yeah, I agree. That's gotta be a big challenge. You feel you're kind of imposing at this really critical time in their lives, of course. So any last tips on how we can better prepare researchers for tomorrow in this field?

Dr. Morrison: The one tip I would say is that researchers absolutely need to be engaged in both advocacy and policy. That we too often are in our own little academic silos and think that our work is done when the project is completed and the paper is written, and in fact that's when the work just begins.

Dr. McPherson: Absolutely.

Dr. Morrison: And that we need to focus on ensuring that the work that we do gets moved rapidly into practice, that we continually are advocating for our patients and our families both at the local, state, and federal levels, and that we're continuing to push for greater funding to improve care for people with serious illness.

Dr. McPherson: Absolutely. Well I would like to thank you both so much. I don't know if you have any remaining thoughts. We've kind of talked at length about research in palliative care and I for one am very excited to have been an observer all this time and look forward to the next, well let's be optimistic, 20 or 30 years. Any last comments from either of you?

Dr. Morrison: Not from me.

Dr. Tjia: No. Not from me, thank you for-

Dr. McPherson: Okay. Dr. Tjia, you're good too?

Dr. Tjia: Yeah. I'm good. Thanks for doing this.

Dr. McPherson: Awesome. Well, thank you both so much for participating. I'm very, very grateful and I'd like to thank all of you, our listeners for listening to the palliative care chat podcast. Again, this is Dr. Lynn McPherson and this presentation is copyright 2019 University of Maryland. For more information on our completely online master of science and graduate certificate program in palliative care, or for permission requests regarding this podcast please visit graduate.UMaryland.edu/palliative. Thank you.