

Speaker 1: Hello, this is Dr. Lynn McPherson, and welcome to Palliative Care Chat, the podcast brought to you by graduate studies in palliative care at the University of Maryland, Baltimore. I am so excited about my guest today, Dr. Jaime Goldberg, who is a research specialist at the School of Medicine and Public Health at the University of Wisconsin, Madison.

Dr. Goldberg, welcome.

Dr. Jaime Goldb...: Thank you so much for having me.

Speaker 1: We're very excited. So by training, Dr. Goldberg is a social worker, and she recently finished her PhD. So could you share a bit more about what your degree was in, Dr. Goldberg?

Dr. Jaime Goldb...: Sure. So I am trained as a palliative care social worker. After my MSW, I did a fellowship in palliative care at the VA in West Los Angeles, and then worked there as well as at Cedar-Sinai Medical Center in LA. Before making this pivot in my career to come back to school in 2018, I joined the Sandra Rosenbaum School of Social Work at the University of Wisconsin Madison because of the faculty here and their focus in health and aging and palliative care. So it was really drawn to the school for that reason, and it was absolutely the right fit for me.

Speaker 1: Wonderful.

Dr. Jaime Goldb...: Thank you. Yeah, it was a great five years if you could say that about a PhD program. I learned so much.

Speaker 1: I know you really enjoyed the quantitative statistics you and I both did, right? Anyway...

Dr. Jaime Goldb...: I'll very, very proudly say that I did a qualitative study for my dissertation.

Speaker 1: Absolutely. And I understand why. So Dr. Goldberg also teaches for us in our graduate studies in palliative care. She teaches in communication and healthcare decision-making and advanced topics and psychosocial spiritual cultural care. And our students absolutely adore her. And occasionally, Dr. Goldberg has spoken in our wises and wonderful Wednesday night series, and we were very excited that for last year, she did one on her PhD research project. So it was so interesting and in many ways heartbreaking. So I asked Dr. Goldberg if she'd be willing to do this podcast to share a little bit about that. So can you give us a little bit of the background, how you came up with this idea and so forth?

Dr. Jaime Goldb...: Sure. I know for so many people who are PhD students, by the time they get to the end of their dissertation, they never want to look at it again. And I can honestly say that my dissertation was one of the most meaningful and humbling experiences of my entire career.

So I, as I mentioned, did a qualitative study. I interviewed adult children who were harmed by a parent in childhood who were then caregiving in some way for their parent who harmed them during their parents' serious illness or at the end of life.

Speaker 1: Well, I had to be heartrending.

Dr. Jaime Goldb...: It was very intense, and I knew that going in, and obviously, when you're doing research, it's different than being a clinician, but I was able to pull from my clinical experience and clinical background to be able to do the interviews and really be present and be able to use all of my active listening and social work skills to be able to be there in that moment with the participants who I interviewed. And I know you asked about how I got interested in this topic, and it was really fortuitous.

I started my PhD in 2018, and it just happened that my advisor, who is just incredible, her name is Dr. Jooyoung Kong. She also started here at the University of Wisconsin in 2018. And when I heard about her research, which is similar to mine, she looks at older adults and their aging process when they need care and lifelong trauma as well. And so she kind of combines those two areas to look at adult children who are caring for their aging parent, who harmed them. And so she uses big data sets, namely the midlife in the US dataset and the Wisconsin Longitudinal Study. Those are two big data sets to be able to look at this topic. And she really found through all of this quantitative work that she did, that the caregivers who were harmed by their parent are experiencing higher stress responses, higher anxiety, higher depression because of their caregiving experience with their parent who harmed them.

And so when I learned about this, my mind was just blown away that somebody was studying this, and I was just so, so interested, and kind of threw a million questions at her the first time we met, and was really excited to extend her research. So I said, "Well, we've never actually talked to these caregivers." Again, she was doing quantitative work with big data sets. So I said, I'm really much more interested in what they have to say and what their experience is. And so decided to do a qualitative dissertation where we actually interviewed them and learned their stories and heard their experiences, and also brought in the piece about serious illness and end of life as well as two other pieces, which was the motivations: why would somebody who is harmed in childhood by their parents stay in relationship and participate in caregiving, and trying to find out from these caregivers what we as healthcare professionals need to know.

Speaker 1: Well, before you spill the beans and tell us the answer to that question, I'm curious, how in the heck did you recruit for this study?

Dr. Jaime Goldb...: Yeah, that is a question that I get so often, and it was something that I was really worried about. So many people said, these caregivers, they're so vulnerable, note, they're caregiving, they have all this stress. Nobody's going to want to talk to you. How are you even going to find them? And it was during the pandemic, so it was even more challenging. And I felt like I couldn't go to the local hospice agencies or

the local palliative care teams and say, can I talk with you about recruiting? Because they were all stretched so thin. And so I did three main things.

The first was reaching out to every contact, healthcare, mental health professionals, palliative care people, clergy members who I knew from my network, and sent individual emails that they then sent out to their networks. And that proved very fruitful. It seems like everyone knows everyone. Everyone knows somebody in this situation, unfortunately. So that was very fruitful.

And then I was very fortunate that three national caregiving organizations agreed to advertise my study in their publications, so either online or their actual print newsletter. And that went out to thousands of people. And several of my participants came from that avenue as well. And then this was becoming more common, but still a little bit unconventional. I actually use social media, and those of you who know me well know that I'm not such a social media person, but this was a really interesting and effective way to recruit participants. The institutional review board said that for good reason that I wasn't allowed to join Facebook groups with the purpose of advertising the study, but I could have a Facebook page and then contact administrators of groups to ask them to advertise the study.

And so Facebook, as many of you might know, has groups for everything. And so I contacted administrators for so many different caregiver groups and so many different survivor groups, and so, and sent them the flyer and sent a little blurb, and they were so kind. They were very, very gracious. And many of them did advertise, and many people contacted me that way. So I ended up doing a total of 22 interviews. I was hoping for five or 10. And then once we got going, I was hoping for 15 or 20, and then ended up doing 22.

Speaker 1: You probably had to turn people away. So you ended up using kind of a convenient snowball sampling technique.

Dr. Jaime Goldb...: Yeah, yeah, exactly.

Speaker 1: So did you do these by Zoom?

Dr. Jaime Goldb...: I did, for the most part. Most of them were on Zoom, A few were over the telephone, but it really allowed me to have a sample that was from all over the United States, so nine different states from across the US.

Speaker 1: That's great. That's wonderful. Well, all I know is in our master of science program, in our very last course, the students follow three patients, and one of them is a man with dementia. So I wanted to make one case really very psychosocial spiritual in effect. So I played the role of the wife of this man who had been abusive of her all their life.

Dr. Jaime Goldb...: Oh, my.

Speaker 1: So my first recording was, I can't wait for him to die. I hate him. And our students were horrified. They said, "I thought Lynn was a nicer person." I was like, "Oh, for gosh sakes, my husband's alive and a well and does not have dementia." So I guess it's time to spill the tea here. What were your findings?

Dr. Jaime Goldb...: Yeah, well, I think it's so wise that you included that scenario because, in healthcare, we often make assumptions. And this is something that I heard loud and clear over and over again from the people who chose to participate in this study that we in healthcare make judgments and assumptions all the time about the adult children and the spouses. And we often use our lens of our own family to kind of overlay or again, make an assumption about what is happening in another family. And so the most powerful quote I think that came out of this entire study was one participant who is in healthcare herself, and she said the term loved one should be banished from the healthcare vernacular.

Speaker 1: Oh, my.

Dr. Jaime Goldb...: And of course, that term is never going to go away, but what she was saying was that we as healthcare professionals need to heighten our awareness that not every family is harmonious, and that when patients and their families come to us, they bring their whole histories and that history may not be roses and rainbows and unicorns. And so that situation that you were describing, the scenario that you use in class is one of the places that I really hope to go with my research because there are all these really complicated relationships and what does it mean to care for somebody who you are in relationship with, but maybe that relationship isn't so great. And so I would love to see a study, and maybe I'll do it someday on adults where the spouse or the partner is caring for somebody who is abusive to them.

Again, this work is really still in its infancy. There aren't that many people doing it. And so we started with the adult children, and now we're getting into actually looking at sibling relationships because that came up during the interviews as well that siblings had very, very different experiences with their parent. So maybe one child was harmed and another wasn't, or they were harmed in different ways. So that is an area that we're growing as well.

But back to the results, which are I think they're really, really fascinating. So I'll just highlight a few. So first, as I mentioned, just being really mindful of these assumptions and judgments. So there may be very good reason why the daughter isn't at bedside all the time. There may very well be good reason why the daughter takes a little while to call the doctor back. And I think that often in healthcare, we label those families as difficult or they're not getting it, or they're not doing what we want them to do. And I think that it's important in those situations for us as healthcare professionals to stop and say, maybe there's something else going on here.

For the majority of participants, they were motivated to participate in care for their parent purely out of obligation. And all of us know when we do something out of

obligation, it is not fun, and it's not how we want to do things. And so they're doing this care really out of obligation, but they're really ambivalent about it. They're resentful and they just don't want to be doing it, but they're doing it anyway. And so being really sensitive to that when we encounter these families is really important.

Speaker 1: So I was curious as you were speaking, did they ever mention feeling guilty that they felt like they were pressed into service to do this, yet that must have resulted in conflicting feelings?

Dr. Jaime Goldb...: Absolutely. So the theme that came out was really obligation and ambivalence. And so the ambivalence piece was really a lot of guilt, a lot of shame for not feeling like they could really be honest or open about the guilt and resentment and anger that they were feeling about caring for their parent, because so many of their peers were caring for their parent with whom they had a good relationship. And it was hard enough. But to be really honest and say, they did tell me, I'm ready for my mom to go. This is too much. I don't want to be doing this anymore. I'm doing it because I have to and I will continue, but I'm done. I'm done.

I asked a very kind of quintessential palliative care question, what are you hoping for in terms of your next steps in caregiving? And so many said, I want my parent to die. There is research. I will just put a little star on that, that there is research that even when there are conflicting and challenging relationships, there can be complications in grief. And that wasn't the focus of this study, but just for those who are listening to know that it can be really complicated. So even if an adult child is saying, I'm really looking forward to being done with this caregiving and having the hardest person in my life, this is actually a quote from one of the participants, I'm looking forward to having the hardest person, the most difficult relationship in my life. And that even into their grief and bereavement, it can be complicated because they feel relief, but then often guilt that they feel relieved, but also there's a mourning for the relationship that they didn't have.

And so for some of the participants, they were caring for their parent, hoping that maybe this little bit of time as their parent was so sick, that they would have a different kind of relationship, or they would hear the things that they always wanted to hear, like I love you, or I'm grateful that you are my child or anything. And for so many, they were not getting any of that during this time of caregiving. And so they were still hopeful and hopeful and hopeful for that. And then once their parent dies, there's no hope for that anymore. And so there are often complications in grief after such a situation.

Speaker 1: Brutal. So you talked about implications of your research. As a social worker or I'm a pharmacist, would you ever bring this up when you're talking to a caregiver, and what would prompt that and how would you go about that?

Dr. Jaime Goldb...: Yeah, it's such an important question, and it was actually a question that I asked participants, would you want to be asked about this? Because in palliative care and

in social work, the patient and the family are a unit of care. So while the person who is ill is our patient, but the family, they're in our care as well. And so we need to take their experience into account. And so it becomes kind of complicated. And for some of the participants, they said, actually, this is a little bit of a tangential answer, but I promise I'll get there. So for about nine of the participants out of the 22, they had a very, very different experience than I was expecting to hear about. So I was expecting kind of only doom and gloom, excuse me, only doom and gloom. And so for these nine participants, they actually told a very different story, which was their parent really struggled with a substance use disorder when they were children. And so these participants were really physically and emotionally neglected as children because of their parent substance use disorder.

Then for these nine participants, their parent went through treatment and became sober, and really came back to their child to make amends and went through their own healing process. And so for these participants, they said that caring for their parent was kind of a second chance at having a relationship, but it was only because their parent went through this amends process. And for them, because of the substance use disorder, they kind of had a lot of resultant medical issues, younger than you might expect. And so their parents, they were ill. And the medical providers that they were seeing for the most part were mental health providers primarily, and they were managing their mental health issues. And then they also had medical providers who were managing the parents' physical issues.

And they really spoke of this great divide that in the mental health world, the child's experience was asked about, was taken into account and resources and support were given to be able to help the family as a unit. And they said that they had a really, really different experience in the physical health realm that they never were asked about their experience.

And for the other participants who only focused on ... they only met medical providers who were focused on the physical health issues, they said they were never once asked about how they were doing as caregivers, what they needed, what support they needed. And so putting that all together, the vast majority of participants said, please ask me, please ask me. I want to share. And again, these are 22 people. It's qualitative work. This is not a generalizable sample. That's not the goal. But they said it just would help us feel seen, and it would help us understand that you understand, you as a professional, understand that we have a different experience than some of the other caregivers who you're encountering. It will help us feel seen and heard, and it will help us to tell our story.

And there were several, I will say just a handful who said, I would never answer that question honestly because I wouldn't want the healthcare professionals to look at my parent differently or risk them caring for them differently because of what they did if they knew that they had harmed their child. But I don't object to the question being asked. I might just not answer truthfully, or I might say we had a difficult relationship and just leave it at that. So I think that this all points to asking sensitively with compassion, with empathy, and not asking for the sake of asking to

pry into somebody's life, but instead asking with the intention of offering support and to build a relationship in a deeper way.

Speaker 1: How would you ask that question? Would you say, were you harmed as a child by your parent, or would you tap the answer around?

Dr. Jaime Goldb...: Yeah, I think that asking a broader question, can you tell me a bit more about growing up in your family or can you tell me a little bit more about your relationship with your parents can be really helpful. And of course, this needs to happen. We need to get permission to be able to talk to the children if the parent still has a decision-making capacity, and this conversation would need to happen separate from the patient or the person who is ill.

Speaker 1: Wow. So what's next? Are you going to publish your research? I think there's a book in your future. What do you think?

Dr. Jaime Goldb...: I would love to write a book, although I will give a shout-out to Dr. Laura Brown who wrote a book called My Turn to Care, and it is ... I'm sorry, Your Turn to Care. And she kind of started the conversation about this. If you do know anyone who is in this situation, Dr. Brown's book, again, Your Turn to Care is a really helpful kind of guide for setting boundaries in these relationships. It's really a help us, kind of a self-help guide for adult children to set boundaries in these relationships with their parent.

Yes. And my hope is to be able to publish the papers that I wrote. One was focused on motivations, as I mentioned before, the second was focused on retraumatization. So 13 out of the 22 participants did experience retraumatization because of the caregiving that they were doing for their parent. And I just want to mention one thing because I know you mentioned in scenario from class that there was somebody ... that your fake husband had dementia. And so I did find that there were participants whose parent had dementia and that parent had hit their child in childhood. And now because of the dementia, the parent was hitting the child again. And so that was just devastating. And I'm encouraged that there's actually another PhD student in another university who is actually doing their dissertation specifically on people with dementia and these kinds of harmful behaviors in childhood and how they come out again in adulthood.

So I'm really encouraged by that. The other piece of the retraumatization that I just want to mention, I would be remiss if I didn't, is just a trigger warning here. All of this is really intense, but this piece is particularly intense because there were several participants who were sexually abused as children, which is just the ultimate betrayal and just absolutely devastating. And they spoke about doing hands-on intimate care with their parent who harmed them.

And one of them talked about having to help with changing a catheter and having to clean up their father ... clean up his protective undergarments, and how repulsive and just triggering that was for her. And again, this is really important I

think, for healthcare professionals to hear. She spoke about the very well-meaning hospice team coming in and saying, you need to go and sit next to your dad. You need to go and hold his hand. You need to go and say goodbye. You need and using the word need, and don't you want to and don't you ... You're going to have regrets if you don't go sit with him. And she was one of the people who said, "I'm not going to tell them what happened in my childhood and how horrible it is to be caring for my dad right now because I don't want them to look at him differently because of what he did, but they need to stop saying this."

And so again, it goes back to that assumptions and judgment piece that she said, my dad and I had a difficult relationship. This is not how I want to spend my last moments with him. I know he's dying. I cannot go into that room. And they kept pushing. So it's really a lesson I think, for all of us as healthcare professionals, just to be really mindful that one size really doesn't fit all.

Speaker 1: Oh my goodness. That is so powerful. Goodness gracious. Well, I know that you are working on an NIH grant on improving communication in the ICU. Do you see yourself also pursuing this line of research in the future?

Dr. Jaime Goldb...: I would really love to. My advisor, Dr. Kong did get a big grant to be able to continue this work and really expand the qualitative piece of it. So if there's an opportunity in the future to be able to work with her, I would really love that.

Speaker 1: That's wonderful.

Dr. Jaime Goldb...: Thank you.

Speaker 1: Well, I wish you well. Anything else you want to share with our listeners before we wrap up?

Dr. Jaime Goldb...: No. Thank you all for listening. I know this can be a very intense topic. And I know that there's been a lot of interest, and so I really appreciate all the questions and you taking the time to listen and improve your care.

Speaker 1: Thank you, Dr. Goldberg, for your very important work. This has been very informative and very heartbreaking, I will say. I just can't imagine being in that scenario. So thank you for all your work.

Dr. Jaime Goldb...: Thank you.

Speaker 1: Well, this is Dr. Goldberg. This presentation is copyright 2023 University of Maryland, Baltimore. For more information about our online graduate studies in palliative care, including graduate certificates, a master of science, and a PhD, or for permission requests regarding this podcast, please visit [graduate.umaryland.edu/palliative](http://graduate.umaryland.edu/palliative). Thank you.