

Palliative Care Chat - Episode 12 - Interview with Chaplain Karuna Thompson and Marty Crittenden

'No One Dies Alone'

- 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 to have two guests with me today. The first is Chaplain [Karuna 00:00:16] Thompson who is with the Oregon State Penitentiary, and our second guest is Marty [Crittenden 00:00:21], who is a nurse. She's working as a school nurse currently but she has about a 15 to 20 year history in hospice care. She also works as a volunteer at the Oregon State Penitentiary training hospice inmates in the facility to provide hospice care and volunteer services to their colleagues in the facility. Ladies, welcome. I'm delighted to be chatting with you today.
- Marty Crittenden: Thank you.
- Karuna Thompson: It's a pleasure to be here. Thank you for having us.
- Dr. McPherson: Definitely. If we could start off with some really broad questions, because I have to say, everything I know about prison life I've probably learned from watching *Orange Is The New Black*, which I suspect is not the best model for getting my information. Could you share with me perhaps Karuna, what does happen with an adult in custody who has a terminal illness? What happens to that individual?
- Karuna Thompson: Of course, yeah. I think it's kind of unfamiliar territory for most folks. The prison where I am is a men's maximum security prison, that in its history has primarily been for lifers, that has changed somewhat. We're having more people who are released from our facility. Because of that, we had our own infirmity inside the institution. You can kind of think of prisons as their own small city or a small town. Our facility has about 2,000 men and all of their food, all of their work, all of their medical is taken care of onsite there as much as possible. For specialists, they are sent out to the community, but for the most part all of life happens inside those walls, including death.
- Karuna Thompson: Because we had so many people who were lifers, about, I would say it's almost 20 years ago now, the lifers club, a group of men who were facing life in prison, realized that they were having friends who were going to the infirmity and who were dying, and that they didn't know what was going on. They wanted to be able to be by them, because one of the things that happens in prison is these very long term, very close friendships, much more kind of family groups are formed. Then this loved one goes to the infirmity and you don't see him and you don't know what's going on. Then you hear that he's passed away.

Karuna Thompson: They really were the ones who pushed to have a hospice program created so that they had a legitimate way that they could go and be with their friends, and really, people who had become family to them through the end of their life. We had a wonderful group of people who went down to the Angola prison and looked at their hospice program and several other prison programs and began to put together a model for our prison. Which is, primarily inmate volunteer based.

Karuna Thompson: Because we have our own infirmity, of course we have our own nursing staff and our own doctors on staff who oversee the program, and a full interdisciplinary team of counselors and spiritual care and acute mental health care, and that meets monthly. It's really, the men, the incarcerated adults who really carry the show and sit with the people and provide the personal care and provide, really, the continuity of care for one another. It's quite an elegant program. At the end of life, the last 24 hours to 48 hours, the practice has been that nobody dies alone. We actually have a vigil and men are able to stay with the dying person until they pass, 24 hours a day.

Dr. McPherson: Wow, that's amazing.

Karuna Thompson: Yeah, yeah.

Dr. McPherson: That's amazing. Marty, what is your role with all this? Could you tell us a little bit about that?

Marty Crittenden: I meet with the men monthly that are the volunteers in the hospice program. I do a lot of teaching about kind of the latest things that are coming out in hospice and share that information. We do a lot of group support with these men, of sharing of their stories and what they're going through.

Dr. McPherson: Do you provide, or does anyone in the system provide grief support for these individuals who have cared for their friends?

Karuna Thompson: It's not as strong as we would hope it would be, but part of the training is that grief support, but also we do provide usually 24 to 48 hours after the death, have everybody who has been working with the particular patient, we get them together to discuss. They don't like the word debrief, so we use the word to process the loss. Then we do put together based on kind of their sharing a memorial for that individual that is held in the chapel, usually within the same month of their passing and includes their friends and community members. It is limited. I wish it were more.

Dr. McPherson: In hospice we often call that de-griefing instead of debriefing.

Karuna Thompson: Yes, yes.

Dr. McPherson: Could one of you tell me, why do the inmates choose to be hospice volunteers? This is a heavy emotional load, why would they want to do this?

Marty Crittenden: Some of it is just because it's gratifying work. Some of them do it because of the guilt that they feel for their past and being a hospice volunteer helps them just be able to kind of give back to society and makes them feel good. One of them actually shared that he started volunteering because he had a friend that was black and was dying, and there were no black hospice volunteers. He decided to do this so that other hospice patients that were black would have a black hospice volunteer to work with them.

Dr. McPherson: Wow, that's amazing.

Karuna Thompson: I think [crosstalk 00:06:38]

Dr. McPherson: I'm sorry, go ahead.

Karuna Thompson: I would add to that just that I think one of the pieces that gets overlooked a little bit is that a lot of the hospice volunteers I've worked with over the years have decided to become hospice volunteers because they knew they would be dying there someday, and they wanted to help create a standard of care for when they faced that.

Dr. McPherson: That makes sense. Is there anything else that either of you would like to add as to what these inmates get out of doing this? Sounds like you've provided quite a few good reasons there. Anything else?

Marty Crittenden: Yesterday evening we had a discussion, actually, with the volunteers to kind of get their perspective and what they specifically they would like us to share, and so that's one of the questions that we addressed. Some of the things that they shared was that hospice shows them how special life is. One of them even commented that if he had known about hospice before he had done his crime, he wouldn't be there today.

Dr. McPherson: Oh my goodness.

Marty Crittenden: It impacted him that much. They also feel like, again, they're family to the patients and a lot of them have done harm to a lot of people, so sorry, and can't change that but feel like by providing care for the other inmates that somehow they're making up for that.

Dr. McPherson: You feel like not only is the hospice volunteer changing the lives of the people who are terminally ill, but functioning in this capacity has also changed the hospice volunteer themselves. Would you agree with that?

Marty Crittenden: Oh yes, very much so.

Dr. McPherson: Yeah, Karuna, are you on board with that one too?

Karuna Thompson: Definitely, definitely. No, they express that again and again of, I think in many ways we talked about it if, you know, people go through their dying process and that's a massive transformation in itself. The volunteers really are the ones who end up kind of carrying whatever that message was.

Dr. McPherson: Absolutely. I know I often think of, I've read or seen on TV about people who live in a prison have often been used in the capacity of training dogs. You know, like seeing eye dogs and things like that. I'm a big, big dog lover, thinking to myself how difficult it would be to let the dog go after you have spent so much time with him. I mean, I know a dog is certainly different than a human being, but this must be very difficult on the volunteers. What is your experience with that?

Karuna Thompson: Well, my experience is there's tremendous grief and there's tremendous bonding. One of the pieces that we've kind of worked to integrate a little bit and sometimes can't be as successful with as we'd want to is trying to give people a gap between clients so that they can feel the loss and go through the loss before stepping in with the next person. Sometimes we're able to do that and sometimes we're not. It really, some of them, it will rattle them. We've lost volunteers, but like any volunteer program we have kind of regular attrition where people come in and they sit with one client and they're really moved by it, and discover that's all they want to do. They don't want to do this anymore. It's too hard.

Dr. McPherson: Yeah, this is hard work. This is very hard work.

Karuna Thompson: It's incredibly hard work. You're loving somebody and they die. That's [crosstalk 00:10:19]

Dr. McPherson: Yeah.

Marty Crittenden: That really makes it very different in this setting too, because not only are these men the volunteers but they're the family too. They're doing dual roles and I think that's incredibly hard and heartbreaking. I know one of the gentlemen commented that, you know, a piece of him goes when somebody dies, but also as he lives on he carries a piece of that person that died, and I like that. Very poignant.

Dr. McPherson: Yes, I'm sure they often, in addition to finding this to be very difficult, find it to be inspirational in many ways. Has that been your experience as well?

Karuna Thompson: We had a really interesting comment last night from one of the men who is one of the newer volunteers, but he was a Vietnam veteran in prison for some pretty violent crimes. He describes that his wife used to think that he was morbid because he liked going to graveyards and sitting in graveyards and that

he felt at peace there. He talked about, that the first time he sat with a patient was just before, it was about six hours before the patient passed, and he actually heard the death rattle and he was there with him. He felt like he had come home and like he was completely at ease and peace for the first time in a long time. I kid you not, I was kind of brought to tears listening to him, because it was the first time I'd heard this man in all the years I've known him really soften when he was talking about this. There is something, I think that opens up for them. For some of these guys, it is their calling as much as it might be for us on the streets in a similar way.

Dr. McPherson: I'm curious, what kind of training do they go through to assume this role?

Karuna Thompson: We based it on the 40 hour outside volunteer curriculum, the idea being that it would be community standard care. They have to jump through the same hoops and go through the same exercises and sit through the same long classroom hours in the middle of the summer, which is never fun, and get rigorously trained and then have monthly training that continues. It's all kind of palliative care theory. They used to be able to provide a lot more kind of in contrast to community care, they would actually provide a lot of the physical care. Because of safety concerns, that has stopped as much so there's more limited physical contact. However, they still are the ones who really know them best. They know when they're in pain. They know when they've had enough or when they need to have fluids. I mean, they are just so incredibly attentive to one another, it's remarkable.

Dr. McPherson: Now, do they carry this function out, I assume that, you spoke of your infirmity, which I guess we would liken to an inpatient hospice.

Karuna Thompson: Mm-hmm (affirmative).

Dr. McPherson: When you have inmates that are not quite so ill that they need to be in the infirmity, but they still are quite ill, I guess living in the general population, do your volunteers play a role there also?

Karuna Thompson: Not at this time. We would like to make that transition, and that's kind of the idea of moving more to the palliative care model.

Dr. McPherson: Sure.

Karuna Thompson: Unfortunately, a lot of men reject the idea of having hospice care because they have the community model in mind, which means, you know, when you sign that paper you're no longer going to seek further medical treatment, further curative measures. In the prison, we don't have to have them sign that for them to receive hospice care. They can continue fighting and still receive this care. In fact, we're required to provide that care if they want it. Our hospice can kind of function in a very different way. Which is why, again, we're looking more towards changing it to a palliative care model.

Dr. McPherson: I see. Can these volunteers administer medications, or is that still under the purview of the nurse?

Karuna Thompson: No, that is all nursing staff and medical staff.

Dr. McPherson: That's what I figured, yeah.

Karuna Thompson: Yeah, yeah.

Dr. McPherson: If you had to sum it up, both of you, what do you think these hospice inmate volunteers would like our listeners to know about them, end of the day? Any thoughts?

Marty Crittenden: One of them wanted ... Go ahead Karuna.

Karuna Thompson: Go ahead Marty, no, you ...

Marty Crittenden: I just was going to say that one of the volunteers had said that they want everybody to know that it's not like a James Cagney movie where they're wearing striped uniforms and are these hateful kind of people. That they want people to know that they're like anybody else. They are compassionate and kind and caring individuals.

Dr. McPherson: Wow.

Karuna Thompson: I think that kind of underlines just the depth of caring that they have for one another. We should be so lucky.

Dr. McPherson: Yes. Well ladies, I congratulate you on what sounds like a very successful program under sometimes very trying circumstances. Is there anything else you'd like to share with our listeners before we wrap up?

Karuna Thompson: I think that that's it. Just mainly that these are real human beings facing real loss and real pain and real illness, and they are doing their best to take care of each other through it.

Dr. McPherson: Is there anything that we can do as a community, outside of your system, to help?

Karuna Thompson: You know, donations are always welcome.

Dr. McPherson: Financial donations you mean, right, okay.

Karuna Thompson: Financial donations so that we can provide things like, not tape machines, but kind of iPod listening machines and those kind of resources and music and DVDs and those kind of things for the men who are dying. They would be welcome to

contact me and I can share my contact information if that's helpful or appropriate.

Dr. McPherson: Sure. What would you like to share with us?

Karuna Thompson: My contact information, my office phone is 503-373-1350, again 503-373-1350 and you can also reach me by post at 2605 State Street Salem, Oregon 97301 and that would be attention Chaplain Thompson care of Oregon State Penitentiary.

Dr. McPherson: Wonderful, and if someone did want to send in a check, make it out to Oregon State Penitentiary?

Karuna Thompson: Oregon Department of Corrections, and then it would be allocated to the Oregon State Penitentiary Hospice Program.

Dr. McPherson: Wonderful. This will be transcribed, so people will be able to read this in case they didn't catch that. Well ladies, I'm very appreciative of your time and your talent. Chaplain Karuna, thank you for your dedication in your career, and Marty for being a volunteer and just so everyone knows, Marty is actually a student in our online master of science program and I was so taken with some of her posts in her work here in the prison that is just so exceptional. Thank you both so much, and hopefully our paths will cross again.

Dr. McPherson: I would like to thank both of our guests and I'd like to thank you for listening to the Palliative Care Chat podcast. Again, this is Dr. Lynn McPherson and this presentation is copyright 2018 University of Maryland. For more information on our completely online master of science and graduate certificates in palliative care or for permission requests regarding this podcast, please visit graduate.umaryland.edu/palliative. Thank you.