Palliative Care Chat Episode 10
Dr. Lynn McPherson interviews Barbara Bouton

Lynn 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 am super excited about our guest today. We have Miss Barbara Bouton, who is the Vice President of Professional Development at the National Hospice and Palliative Care Organization where she does pretty much everything. She oversees and coordinates professional development and continuing education, continuing medical education for hospice and palliative care providers across the country. Prior to coming to NHPCO, Miss Bouton worked with Hospice and Palliative Care of Louisville, which is now Hosparus in Kentucky for 23 years where, among her other activities, she developed a start of the art bereavement program that served hospice families in the community, as well as, staff, volunteer, and community education and support programs.

So just a little bit more about her background, she holds a Fellow Thanatology, which is interesting. Maybe I should ask you what Thaumatology is, is our first question. A lot of people don't know what that is. Through the Association of Death Education and Counseling, a Master of Arts from the University of Louisville, and has over 30 years experience in hospice care, grief and bereavement, end of life care education, and the development of related programs and services.

So, Barbara, welcome. We're delighted you're with us today.

Barbara Bouton: Thank you so much. I'm delighted to be here.

Lynn McPherson: So first, what is a layman's definition of Thanatology? What is that?

Barbara Bouton: Thanatology is the study of death, dying, grief, and bereavement.

Lynn McPherson: Wow. That sounds pretty intense.

Barbara Bouton: Yes. Being a Fellow just means that I know a lot about those things and with all these years of working in the hospice and palliative care field, you would hope so. Right?

Lynn McPherson: Absolutely. Well, I'm sure you are a rockstar at this. So we're hoping you will share some of your insight with us.

Barbara Bouton: Happy to.

Lynn McPherson: That's great. The first question I have here is ... I mean, I always think of grief and bereavement as when someone has died, and thinking about the survivors after the death. But is grief and bereavement part of the person's illness trajectory, as well?

Barbara Bouton: Absolutely. In fact, let me just start with a couple definitions. When we talk about loss, we experience loss anytime something of importance changes in our lives. So with that definition, we are coping with and experiencing loss almost on a daily basis. Grief is how we respond and we respond to loss and to change physically, cognitively, emotionally, socially, spiritually. It's kind of our internal and personal reaction and response to loss. Bereavement is what happens when someone dies and what we experience. It's sort of the state of bereavement or the period of bereavement. Then just to throw one other definition in, mourning is really how a community or society grieves. It's sort of the external expressions of grief and bereavement, as opposed to, our internal, own personal experience, if that makes sense.

Lynn McPherson: Wow. I didn't realize there were so many different shades of gray in this field.

Barbara Bouton: Yes. So anytime something important changes, we experience loss. We think of those as negative, but there can be positive losses as well. Negative losses are things like death, divorce, maybe the loss of a job or a position, shattered dreams, empty nest when your child grow up and leave home. But positive losses are maybe things like retirement. Maybe you have changes in care giving responsibilities. Reaching a goal, realizing a dream, moving to a new location. Even though all of those can be exciting, they also carry a component of loss with them because there is a change.

So the one that I like to recall was when I finished graduate school many, many years ago. I had distinguished myself in my university. I was a teaching assistant. I knew everyone. I knew the campus. I knew the professors. Then I graduated, which is an achievement and an accomplishment; however, you go out into the world and it's like, "Now, what am I?" All of that identity as being a student, as being a teaching assistant was gone. So even though it was the realization of a dream and goal to have that achievement, there was a loss component to it because it was a significant change in my life. It required me to rebuild my life and to rebuild my identity, if that makes sense.

Lynn McPherson: It does.

Barbara Bouton: If you go then and look at illness, when we talk about illness, people coping with illness are dealing with a variety of losses and a variety of changes. They are losing their health. They, perhaps, are losing how they spend their time. Maybe they can't work like they used to. Maybe they can't do their leisure activities. They can't participate in things that used to bring them pleasure. They lose a lot of independence. They lose control, perhaps, over their life, over their health, over their bodily functions.

Two really quick examples. I feel like I have a lot of people in my life right now that are coping with illness. My best friend's husband John is coping with throat cancer.

Lynn McPherson: Oh.

Barbara Bouton: And had a recent surgery to remove the cancer and lost his ability to eat. He has eating tube for a couple of weeks and is now just beginning to eat foods with substance. He was excited the other day that he was getting to have some soup that had chunks, as he said it, in it. So, you know, he was used to pureed food. He went from complete healthy person to person with throat cancer to a person who can no longer eat. So those were a lot of changes and a lot of losses he experienced.

On the other hand, I have a friend Kathy who is coping with breast cancer and next week will have mastectomy. She and I were talking just yesterday, this is a perfect example. She works in theater. She's a competent, independent woman. Our conversation veered into how difficult this was. She said, "I've had a breast for the entirety of my life and I'm getting ready to lose that breast. I don't know what's going to happen. I don't know what to expect." All of those are losses that she's experiencing, and they are accompanied by grief. Probably the most important loss that we discussed was that she is losing ... She doesn't have competence right now. She's used to being a competent person who manages their life, who manages their career, and in this illness, she has lost all competence and is an incompetent person. For someone who values competence, is a very high value, that's a pretty huge loss.

Lynn McPherson: I can imagine.

Barbara Bouton: How's that make sense?

Lynn McPherson: It does makes sense. So I hear this term anticipatory grief. Does that apply to both patients and families who have a loved one who's seriously ill?

Barbara Bouton: Well, generally it has traditionally applied to family. Anticipatory loss or anticipatory grief has to do with what is happening in that illness trajectory to a loved one and how we begin to expect and anticipate what's going to happen. Particularly, if that person's illness is going to end in their death. It's kind of, if you will, practicing what's going to happen. Begin to visualize what's going to happen when that person dies, and all of the changes and losses that are accompanying that illness. So you begin to practice, if you will, your grief. You begin to imagine what life is going to be like without that person.

Lynn McPherson: Sure.

Barbara Bouton: All of the roles and responsibilities you're playing.

You know, the loss of the role of a caregiver when someone dies, is a loss. Right?

Lynn McPherson: Mm-hmm (affirmative).

Barbara Bouton: Because you kind of define yourself, you've spent your time that way, you put a lot of energy into being a good caregiver, and particularly, in a spousal relationship. If one of the spouses dies, then the other person doesn't know who they are anymore. Particularly if they've been a caregiver for a number of years.

Lynn McPherson: I would imagine that if it were a very arduous caregiving role, the relief from the responsibility often could even make you feel guilt for being relieved.

Barbara Bouton: Absolutely.

Lynn McPherson: It can be complicated stuff.

Barbara Bouton: It is complicated. So you have relief, as well as, loss. Then you feel bad that you feel relieved because what am I mean? What am I saying about that?

I have another friend whose mother is elderly. She keeps sort of getting close to the end of her life. Then she rallies and sort of getting close to the end of her life. Then she rallies. She's been doing this for a couple of years. Every time it gets sort of close to what appears to be the end of her life, the families like, "Do we go now? Do we not go now? What do we do? Oh, we wish she would just die so she could have some peace." Then, of course, what accompanies that is, "Oh my gosh. How could we say that? How we could wish that?" Their wish is for her peace, but still you get caught up in all of the thoughts and feelings. What kind of a terrible person am I to wish that her life would be ended, right?

Lynn McPherson: Yes. That is complicated. So you've been talking about these stages of grief and I know there's lots of theories. I always think of Elisabeth Kubler-Ross and the stages. I'm a very organized, OCD kind of person. So it seems to me like there are rules and you should march through these stages and don't ever look back. But I suspect that's not the case. So could you share a little bit about how some of these theories differ amongst the different theories, and what's current and what are our understandings today of grief and bereavement?

Barbara Bouton: Yeah. All of that is very complicated. You're right. Everyone who goes through grief and loss and bereavement wishes it was as easy as first I'm doing this, then I'm doing that, and I'm going to progress through this naturally. Then I'm going to be done. But, unfortunately, it doesn't work like that. You know, the way we respond to grief and loss is generally normal and very healthy. It is individual and unique. Very multi-faceted and ebson flows. But it doesn't progress in neat steps and orders. So for your OCD tendencies, being in the midst of grief and loss would be pretty challenging and the experience of grief and loss occurs over a long period of time, much longer than society expects and much longer, most of the time, then we expect. Because we have expectations. Gosh, I should be doing better now than I feel like I am.

But in terms of perspectives and theories, you're right. There are a boat load of theories about grief. Kubler-Ross was one that was used often to describe the bereavement, I.e., after death process. But really her work was focused on

before death, the dying person's experience. Even though she said this process doesn't fold in predictive steps or stages, most of the time people think of that as a progression of denial, angler or bargaining depression and acceptance. Then whoa, we reach the top of the mountain. All is well. But it doesn't necessarily work that way. So Tubler-Ross' work and even Freud had ideas about grief and bereavement and wrote about them. You know, we're sort of the beginnings of our thinking about and really paying attention to grief and loss.

Most contemporary theories are Bill Warden who developed tasks of mourning. A lot of hospice bereavement programs use Warden's work. It is really great work, and it's also easy for people in bereavement to understand. A lot of the theories about grief and bereavement, the stages or states of grief, have to almost make it sound as if there's something that happens to us. We go through these states or these stages. Whereas, Warden's tasks of bereavement really give us activity or actions that we can do. It helps us to feel more like we're in control, if you will, of our grief and loss. So Warden's task are the first to accept the reality of a loss. Secondly, to process the pain of grief. Thirdly, and this is the biggest one, it takes people the most amount of time to adjust to an environment in which the deceased is missing. Then fourth, define to enduring connection with the deceased. As you're sort of creating this new identity, embarking on a new life, you are developing, creating a new relationship.

When Freud did his work way, way back in the day, he came up with an idea that what we have to do in our grief is a process called Deak of Texas. He said between people there's energy, there's an exchange of energy in relationship. When a person dies, that energy exchange is cut off and our task, he said, is to pull the energy back into ourselves and to be severed from that relationship. Fast forward to current day, another one of the theories, if you will, is about continuing bonds. We don't pull all of our energy back. We have a relationship. It becomes a relationship of memory versus a relationship in the physical world, but it's still a relationship. The emotional attachment continues, although it was considered to be really pathological and not a good thing, back in Freud's day. The continuing attachment is accepted now and the research shows that's a healthy thing when the attachment bonds are secure and that serves us very well to think about those relationships and continue to make those people that have been lost in our lives part of our daily life. We all have experiences and rituals and activities that we do that bring those people back into or keep those people in our lives, if you will.

Lynn McPherson: I just read a commentary by a bereavement counselor at a local hospice here in Maryland. His mother had died this past year. He said that his family chose to take one ritual to use every year during the holidays to honor her memory. Do you think that's good way to go?

Barbara Bouton: Absolutely. Very much. To either identify something that has been part of a tradition in the past or to create a new tradition. In my own family, when I began to lose family members, at Thanksgiving at our Thanksgiving table we would light a specific candle that was symbolic of a specific individual. Now, it has

progressed as life continues, we have too many candles that won't fit on our dining room table. So we have little votive candles that we light and we say the name of the people and we surround the table with these candles as we have our dinner. It's like they're still with us. They're still a part of this. It's really important and meaningful to bring them to the table, if you will, to recall that they're still part of this family. So those kinds of activities can be very helpful.

Lynn McPherson: Now, you have described all these theories, which sounds pretty complicated to me. But then I also hear about complicated grieving or complicated grief. What is that and how is it different from what you described, and how can we, as hospice and palliative care practitioners, recognize it?

Barbara Bouton: Well, it's really hard to recognize. There are a lot of differing thoughts and a lot of conflict, I would say, in the field of bereavement about what complicated grief is. You know, back in the past, we thought of complicated grief, it had a lot of different names. Unresolved. Chronic. Pathological. Formerly, it was also associated with very specific types of loss. For example, the loss of a child, the death that occurs by murder, those kinds of things. But now that's not the current understanding. There are new definitions, ideas, and strategies, I think. Lots of new terminology. Complicated bereavement. Traumatic bereavement. There's another prolonged grief disorder or this one, my favorite, persistent complex bereavement related disorder.

Lynn McPherson: Good grief.

Barbara Bouton: All of these people that have come up with them have different ideas. Although, there's some components that are, you know, consistent across them. In a nut shell, I would say, it has to do with the amount of time that has occurred since the death and the intensity of the loss experience, the grief experience. There are some risk factors, some red flags that might indicate that in particular circumstances people are likely to do more poorly than others in coping with loss. Things like if it's a spousal loss or the death of child, especially the mother may experience more difficult grief. If the relationship or the attachment in the relationship has been one of anxiety or there's a voident attachment or insecure attachment, if there's a lack of social support, if there's a lot of dependency in the relationship, that can be a difficulty after death occurs. So those are sort of the red flags. That doesn't mean the grief is going to be complicated, but it means there might be some problems.

The definitions that are being put forward now and that are being looked at seriously for a "diagnosis" of complicated bereavement or any of those other fancy terms that I mentioned, has some symptoms that are reminiscent of PTSD.

Lynn McPherson: I see.

Barbara Bouton: Lots of anxiety. The criteria for that diagnosis, if you will, is that death has occurred at least maybe 12 months before ... Six to 12 months. Some theorists are promoting six months, some of promoting 12. There's a lot of separation

distress on a daily basis. There's a good ole British terminology yearning and pining that came from early grief theorists. But intense sorrow and emotional pain. A lot of preoccupation with a person that died. Preoccupation with circumstances. What happened at the time of death? In that early stages of grief, those are very, very normal. It's when you have this time factor where it doesn't change over a long period of time that is a concern. If the intensities really high. There's also a reactive distress. There's difficulty even accepting that the death occurred. A person, for a prolonged period of time, may seem to be in those early stages of shock and numbness and denial. This really didn't happen. They can't remember anything positive about the person. Or there's a social or identity disruption.

What makes complicated bereavement so complicated is that the majority of these criteria are very normal in the early stages of bereavement, but they become less so the longer time has occurred. When the intensity doesn't decrease. So what you expect to happen over time in normal "grief" is that if there's any such thing is that marked intensity and distress becomes lessened over time. Some people will find a way to return to some degree of equilibrium in their life.

Lynn McPherson: That's got to be difficult though to pick up. Like I sit at hospice team meeting and first we do the deaths, and I hear the nurse case manager say to our bereavement coordinator, "I anticipate normal grieving." How can they tell at that point that they anticipate normal grieving? Then every time you say, "Oh, you should be getting over this by now. It's started to look a little complicated here." The answer is always, "Everybody grieves in their own way." So how do you reconcile all that?

Barbara Bouton: That's why it's so complicated, if you will, and why there's so much conflict within the field about what is complicated grief and when is it complicated and when is it not. There are a lot of theorists and practitioners who are working really hard on this and trying to get it as clear as it can be. I would assume that person in a team meeting who is saying, "I expect normal grief," maybe is aware that none of those risk factors are present. You know, this is a person who's socially very connected, very active in their environment or their community, has a lot of friends, has a lot of family support, has meaningful life activities. But, you know, it's not something you can just predict. You have to let it unfold over time and watch it. That's why, at the time of death or immediately after, you're not likely to know whether a person is going to be in a complicated grief situation six to 12 months down the road because it can look really bad early on in grief. People often think they're going crazy. They have lost their mind.

One of the most important things, I think, that practitioners and students in this program can do is learn about grief and bereavement, learn about what's normal, and help people understand and learn that this is what grief looks like. Oftentimes when I talk to people, they'll say, "This is happening or that's happening. I'm doing this. I'm thinking this. I'm feeling this." I'll say, "You know what, that's called ...."

"What? What?"

"It's called grief. That's just part and parcel of the experience."

Lynn McPherson: So when a hospice follows a bereaved individual for 13 months, would they be likely to pick up on grief that's become complicated, do you think?

Barbara Bouton: Yes. I think they would know over time. They would expect to see a natural progression of a person having a period of extreme disequilibrium and not knowing who they are, what they're about, what they need to do, and then starting to sort of put their life back together.

Lynn McPherson: Yeah.

Barbara Bouton: Your question reminds me of a woman many years ago we had in a bereavement program, who was in a hospice situation. Her husband had died very suddenly. Had a massive heart attack and just died on the day that he was doing some volunteer work at his church. Oh, maybe three, four, five, six months later, she was in a bereavement group and was talking. She was really angry that he had died. Spring was coming and she had to do yard work and that was his job and why wasn't he there. She didn't know how to ride their riding lawn mower. She was just completely fed up with the whole thing. Then two or three weeks later, she came into group and she said, "Well, I cut the grass." It was like, "All right. She's going to be okay."

I said, "Congratulations."

She said, "I didn't like it."

I said, "Well, you don't have to like it. The fact is you figured it out."

All of the many years that I've worked in bereavement, I came to believe that there's a decision point. There becomes a point and time and it's going to be different for everyone. It's not necessarily conscious, but it's I'm going to figure this out. I'm going to figure my life out. I'm going to figure out who I am. I'm going to figure out how I go forward. Or I'm not. And it's the people that don't make that decision point that are going to be at risk.

Lynn McPherson: So as hospice and palliative care providers, how do we provide good self care and our own resilience when working with bereaved individuals because it seems to me that it could suck the life right out of you.

Barbara Bouton: It can absolutely suck the life right out of you. You know, the people that are working in this field are human beings with human reactions. Generally, you get involved in the field because you're a caring person and you want to help others, which makes you vulnerable too. So not only are you faced with all of these people you're working with who are coping with profound loss and grief in their

lives, we have our own histories of loss and grief too, our own experiences. Sometimes those get kicked up when we're working with patients and families. We have to be aware. We have to be self aware enough that we know when our own histories are kicking up and might be influencing how we are being helpful or, conversely, not helpful.

I think what we have to do is practice radical self care. Whatever that means for you, figure that out. For some people it's something very active. For other people it's very meditative or something that's restorative. Sometimes it's with people, for some of us. Others it's don't put anybody around me, let me have my own quiet time. I think the important thing is to know that you're going to be effected, expect that you're going to be effected. Some situations, some people, some relationships will be more difficult than others. Practice this radical self care. There is a lot of concern in this field about compassion fatigue and burn out. The real liabilities for individuals in working in this field. There's a lot of research that shows ... Particularly focused on physicians that it's not good. There's a lot of work that needs to be done to guard against that and take care of ourselves. I think oftentimes people in this field pride themselves on being good helpers, want to be helpers, but sometimes we are more focused on others and degate our own needs.

Lynn McPherson: What happens when you're a healthcare provider, you "should know better" because we're all enlightened, but you've had a personal loss. Like I was just telling you the story about how I was wrapping Christmas presents this past weekend and I reach for a gift bag because we recycle in my family. It said to mom, from Lynn. My mom died this past May. That was like standing with my back to the ocean and a 10 foot wave crashed over me. I did not see that coming.

Barbara Bouton: Well, that is part of how grief unfolds. It just hits us and can drop us to our knees when we least expect it. I've heard people talk about going to the grocery store, you're just kind of, "Okay. I'm having an okay day. I'm going to go get my groceries for the week." You walk down an aisle, and you just happen to look over and see your spouses favorite food. It just completely takes you off track. It just is what happens. I think what we have to do when that happens is go, "Okay. There it is again." Not say, "Oh my gosh. Somethings wrong with you that you're feeling that way." It's very normal.

In your situation, you are reaching the first Christmas. That is pretty loaded. Holiday times are so difficult when we are missing someone that has been part of our lives on an ongoing basis. I think we have to find rituals and practices to help us with those times. When my own mother died, the first Christmas, i think I was putting away decorations, and I came across some stationary. It was Christmas stationary. So I sat down and wrote her a letter. It was probably three pages long. I put it in an envelope, put it in with the Christmas decorations, and then every year I got it back out, I read what I rode the year before. I would write a new letter on the ... Just continuing for ... I don't think I have done it now for a couple of years. I haven't found that yet in my Christmas decorations, but it really helped me. So you just have to look at things that will be helpful at ways

that we can continue to maintain those relationships and translate them into a different kind of relationship.

Lynn McPherson: Good advice.

Barbara Bouton: It really helped me to get through those tough times.

Lynn McPherson: That's great. Thank you. As we close, Barbara, anything new and exciting on the horizon for NHPCO and upcoming cool programming you want to share with the group?

Barbara Bouton: Well, you know, NHPCO has a podcast that is happening twice a month too. Mainly on regulatory related topics. That will continue into the new year. We're planning a virtual conference for the summer that will be on transitions in care. All of the different types of transitions that people will go through throughout their illness, and how to help people navigate and manage those. How we can do a better job, as well as, gearing up for a management and leadership conference. Our fall interdisciplinary conference, which will be in New Orleans and I'm happy that you're going to be there, I hope, right?

Lynn McPherson: Wow. New Orleans. I have to be there. Are you kidding?

Barbara Bouton: New Orleans. That's right.

Lynn McPherson: Got to love a good beignets. I know that all of us who practice in hospice and palliative care are very appreciative of NHPCO's efforts, not only in education but in advocacy and keeping everyone informed and trying to swim the political stream. Boy, that can be pretty challenging, I'm sure. So thank you for a, doing this podcast for us, personally, as well as, the organizations efforts.

Barbara Bouton: You're welcome. Thank you for the opportunity.

Lynn McPherson: Well, you're certainly welcome. Thank you.

I'd like to think Miss Bouton and I'd like to thank all of our listeners for joining in for our Palliative Care Chat podcast. I do what to point out that part of our Online Masters of Science and Graduate Certificate Program does include coursework in Thanatology either as a certificate or as part of the master's program. For more information about our program or for permission request regarding this podcast, please visit Graduate.UMaryland.edu/Palliative. Thank you.

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