

Episode 7 - Dr. Deborah Waldrop: End-of-Life Care for Our Nation's Elderly - Methods and Challenges (part 2 of 3)

[00:00:08] Welcome to living proof a podcast series of the University at Buffalo School of Social Work at www.socialwork.buffalo.edu. Celebrating 75 years of excellence in social work education. We're glad you could join us today. The series Living Proof examines social work research and practice that makes a difference in people's lives. Today's podcast is the second in a series of three featuring Professor Deborah Waldrop in a discussion about her research on end of life care for a nation's elderly. Professor Waldrop is an expert in End of Life Care a Hartford scholar and a faculty member at the School of Social Work with 25 years of practice experience. In this segment Professor Waldrop discusses the aims and methodology for her research on end of life care decision making and some of the challenges to conducting this type of research. Providers of end of life care need to understand better what people are telling us what people are experiencing because they don't understand it. And so that's my goal is to be able to communicate that and finally because research at End of life is important for improving care not just for this patient population but for society for humanity and for all of us in the long run. So the aims of my study were really twofold I wanted to develop and pilot test and organizationally specific protocol. That was the first Phase 1 and Phase 2 was to investigate the participants perspectives on the factors that really contributed to how they made that decision when they made it.

[00:01:46] In other words the timing of that decision on their trajectory of illness that the circumstances that surround end of life are very very poorly understood. There are ambiguous definitions. There's there are difficulties in measurement. There's fragmented ways of measuring concepts and constructs in end of life care and that all hinders you know a greater knowledge about how we provide it. How is it that we understand the way information is processed at this time and how do we talk to people about the decision to use or not use these services. So communication among patients families and providers is critical and if life researches has been previously often conducted with surrogates for the challenges that I'm going to about to share with you. It's not easy to talk to somebody who's dying about what it is that's happening to them. So in one way that we've sort of circumvented that is to talk to family. We've also found that surrogate information is not an accurate way of necessarily capturing the experience it needs to come from the person who's experiencing it. Data is often collected afterwards so it's secondary data in the sense of post you know post death data that doesn't reflect accurately either. People think that if you ask people about their experiences it's going to distress them. And there have been a couple of studies in a couple of articles written about the fact that if you ask questions in a sensitive way and you were present with people and you understand their experience that it does not cause undue distress gathering personal perspective is crucial. We need to research this in the moment.

[00:03:13] From the mouths of people who are experiencing it and the recognition of that needs to include individual's voice is not what we think they think or what they think they experience but what they actually will tell us is their experience. It's moderated by ethical issues personal realities challenges of research with people who are dying and here are the big ones frailty people who are dying often have very little physical stamina. They may tire very quickly they may be nauseated or experience pain. They may be sleepy. Their capacity wanes from time to time. Their symptoms may be what's the first Farooque focus for them not necessarily that they want to talk. They might want to talk with me or talk with a researcher but the symptoms are the first first issue of time for my medicines. Those kinds of things and then caregiving caregiving is time consuming. It's scheduled around the person's daily routine. So finding just the right moment in which to ask the questions we need to ask is really pretty challenging their issue. There have been issues in the literature raised around voluntariness. Do people feel compelled or forced or coerced into this research. And so

addressing capacity even if the capacity is clear when I send a letter out or when I make the call I have to assess that capacity when I'm present with somebody because it can wane it can wax and wane so so quickly and then recall of end of life events even recall the things that happened in the hospital before they went to hospice can do them pretty quickly. So you really were sort of dancing around and you know time is of the essence.

[00:04:39] The methods I used were to develop an exploratory developmental two phase process in which I really hope to get all this done the first phase which started over the summer was to develop the recruitment policies. And this involved be submission which was actually simple compared to the meetings with all the team members and all the administrators and then questions lots of questions and then more questions after that about how are you going to reach these people what are you going to ask them how are you going explain it over and over and over and over and all that should happen all of that should happen I think about it a lot like creating. You know when steel goes in the oven it gets pounded it goes back and it gets pounded the protocol just kept continually taking shape. What we ended up with is for hospices that have written letters of intent and participation. The protocol was too invasive for one it we developed an extremely labor intensive recruitment protocol. So here's the protocol that we came up with. We sent an information letter in all packets then the hospice's developed for me a list of names and contact information on each of the patients who meet my study criteria which are over age 65 and have been on the program for two weeks or longer. That was an absolute they wanted me not to be talking to people within the first couple of weeks when the team is just forming their rapport and relationships I had to agree to wait the two week. I had to tell them that I would do every single interview. There would be no students based on my history with the hospice's. They wanted to make sure that it was somebody with some experience doing this.

[00:06:10] So then what happens is I mail out a letter and a mail response forms to everyone who meets the criteria on the list. They they write write back to me or they send me back the form if they're interested then I make phone calls with them. And again time is of the essence. Thank you for your interest in my project. When may I come and see you. And so that means clearing my schedule to be available so that I can see them when they need to be seen. I make a confirmation phone call on the morning before I start out in a number of times I've called and the person is either very very ill or this is not a good day. So that's a critical piece of the of the protocol. It's inclusive so that if I get out there and the person says I really don't feel like talking to you but my daughter is willing or I don't want to do this without my daughter. I'm all comers. I'm going to talk to whoever is there. It's not been only the patient or only the caregiver I'm just I've cast a wide net in this project to really see what happened and then I do in person in-depth interviews they are conducted at the bedside at the kitchen table or in the living room. Ninety nine percent of them have been in the home. We have a waiver of authorization under Himba which this this research would not be practicable without a waiver. They gave me only the information I needed.

[00:07:22] So I don't have a lot of information about each of these people but I do have enough to write them a letter. There were a few surprises. Those were two irate phone calls you might expect and a changed protocol. We sent. We put letters in the information packets to all new patients. We didn't put we didn't somehow notify all the existing patients. And then when I went to send letters to existing patients who didn't know this project was ongoing. Two of them said How did you get my name. How is it that you gave my name to the university. We composed a letter to write to these people. We explained to them that it was voluntary that you know that they had given the information to me only it wasn't to the entire university and ultimately the most irate phone call that woman. After hearing the explanation said I'd like to be interviewed. You've been listening to the second of three podcasts featuring Professor Deborah Waldrop discuss her research on end of life care decision making. Visit our website to hear part three of his series in which Professor Waldrop shares with us participant experiences in their own words. Hi I'm Nancy Smyth Professor and dean

at the university at Buffalo social work. Thanks for listening to our podcast. Our school is celebrating 75 years of research teaching and service to the community. More information about who we are our through our programs and what we do. We invite you to visit our Web site at www.socialwork.buffalo.edu. At UB we are living proof that social work makes a difference in people's lives.