

Episode 2 - Dr. Deborah Waldrop: End-of-Life Care for Our Nation's Elderly - History of Hospice Care (part 1 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. I'm your host Adjoa Robinson. Today's podcast features Professor Deborah Waldrop in a discussion about her research on end of life care for our nation's elderly. Professor Waldrop is an expert in end of life care and Hartford scholar and a faculty member at the School of Social Work with 25 years of practice experience. This is the first of three episodes in this episode. Professor Waldrop explains the personal nature of studying end of life care and answers the questions. What does hospice care and what is its history. What I'm going to be reporting on today is are presenting to you is very very preliminary data from a pilot project that I've been funded through the Buffalo Center for Social Research. And I want you to know that I just started collecting data in September. So it's a little bit preliminary but again it's in qualitative data analysis it's really helpful to put out there what I think I'm seeing get some some feedback from you. So that's kind of where we are. We haven't a cutting edge really state of the art hospice organization in Buffalo and Erie County. This research is about end of life. And so at the end of the day it is personal.

[00:01:44] And I just want to acknowledge that because some of our colleagues came to me and said I really don't want to hear this if it's about dying. So it's you know this is about dying. That's what I do in my way of looking at it that sun goes down the sun comes up and dying is part of life and so it is only by asking and by listening that we will understand what that process is about. So I just put that out there as my image for you. And my view about care about about end of life care particularly is that we'll never know how to improve care for people who are dying unless we ask people about their experiences about what works for them and how to improve it. And if we ask it in the moment and that's what this is about is asking people in the moment what their experiences have been and what they needed how they made their decisions. This is from Albert Schweitzer who said we all must die but if I can save someone from days of torture that is what I feel is my great and ever new privilege. Pain is more terrible Lord of mankind than even death itself. And that's the other reason that I do research and end of life care is I believe in change through research. And I hope that the work that I do will help make a difference in the in the future ending of of people's lives so that's that's the whole sort of premise of what I did why I do what I do. So let me give you a little bit of background. There's a really incredibly changing context. Perhaps you've heard of it's been in all the news.

[00:03:08] People are living longer. They're living well into their 80s and 90s. There's that the demographic imperative is what it's being called the growing numbers of people over age 65. And because of that it really shapes the social context in which we live with long term chronic illnesses life threatening illnesses. And it shapes the context of our later years. So there's real important information that we need to gather about how to make that those that time period better for those who will be living it. There are services that are available. What I've found in that in the years of work that I've done is that these available services are not used at all to the fullest fullest extent and when you look at differences across the region for instance from in the city area from Buffalo into rural areas there's huge differences. So they're either they're out there and people will say well there's hospice but Hospice isn't the same everywhere. So that's one of the pieces of background it's important to mention.

[00:04:03] And you know yes it is a pun on words hospices shrouded in myths right okay and

misconceptions and so we really need to take that apart and deconstruct some of what people believe about or what they don't understand about hospice and that's another important part of the background for this project and then finally what influences people's use or nonuse of hospice services and so that's really what brought me to where I am in terms of this project hospice was initiated back in the 60s probably before that actually but the first data record was in 67 when Cicely Saunders who by the way was trained as a physician a nurse and a social worker. She founded St Christopher's in London which was the first hospice and it was the word hospice really comes from the word meaning a word meaning hospitality and a shelter for the weary on the long journey. And so those initial hospices were community based residences very homelike very warm very much you know a natural transition from perhaps being able to live independently into a facility where your needs would be met. Hospice came to the US in 74 and it was not at that time a benefit that was covered very much by any insurance company until 1982 when it became a Medicare benefit. And from that day forward I've actually had people tell me it went from being a movement into a mechanism and now hospice really has been structured in a way that benefits are delivered greatly by the Medicare benefits so that's one major change that's occurred and since that time there's been a real morphing of the process a real evolution of what it looks like and I'll share some of that with you as well one of the other really significant dates was 97 which was just 10 years ago is that the Institute of Medicine did a report looking at the ways people die in our country and they reported on the great needs to improve care at the end of life to talk to greatly about the disparities in the experiences that people have as they reach life's.

[00:05:58] And since that time there have now developed five essentially five levels of hospice care hospice care for people who are within six months of dying have a life threatening illness that will end in death within six months and it can be provided in the home the majority of hospice care is provided in home care settings and in people's own homes. It also can be delivered in hospital based rooms that are considered swing bed. Hospice care can be delivered in nursing homes. Many of the nursing homes in our region in our county have contracts with nursing home organisations. It is also offered in a freestanding hospice inpatient unit and this is the one in Cheektowaga so that's and then the final the fifth level of care or hospice houses which are again freestanding units that are not medically based. They're more of a residence and there are enough 4500 hospice organisations in the country. Steady increase every year as well there is a steady increase in the numbers of patients who are served by hospice every year to a record number of a million 300000 in 2006 and in 2006 44 percent of those people who were admitted have cancer. 56 percent have non cancer diagnoses and then that's bad. It's been going the average length of stay is a couple of months. And the median length of stay twenty point six days or six months or longer and people are using it only for less than three weeks. By and large more people use it for less than three weeks and use it for anything longer than that. The majority of the people who use hospice services are 82 percent are over 65. So roughly one in three of our older population will use hospice services in one form or the other.

[00:07:41] 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 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. You've been listening to Professor Deborah Waldrop discuss the history and nature of hospice care in the next episode. Professor Waldrop discusses the challenges of asking people in the moment about their decision making concerning end of life care. Hi I'm Nancy Smyth professor and dean at the University of Buffalo School of 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 history our programs and what we do. We invite you to visit our website at www.socialwork.buffalo.edu. At UB we are living proof that social work makes a difference in people's lives.