

inSocialWork Podcast Series

Episode 57 - Dr. Robert Milch and Dr. Donald Shedd: Good Outcomes at the End of Life: The History of Hospice Buffalo

[00:00:08] Welcome to living proof a podcast series of the University at Buffalo School of Social Work at www.socialwork.buffalo.edu. 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. The University at Buffalo School of Social Work is making a difference every day through the generation and transmission of knowledge promotion of social justice and service to humanity. We offer MSW and PHD programs continuing education programs and credits online courses licensure exam preparation professional seminars and certificates and much much more. To learn more about the UB School of Social Work please visit www.socialwork.buffalo.edu. This is your host Adjoa Robinson a good outcome at the end of life. That's how Dr. Robert Milch describes the goal of hospice services. Dr. Donald Shedd are today's guest on living proof. Dr. Robert Milch is a staff physician and medical director emeritus for the Center for Hospice and Palliative Care in Buffalo. Dr. Milch joined hospice buffalo in 1978 as a volunteer medical director and has been a leader in hospice and palliative care for more than 30 years. Dr. Donald Shedd is a professor emeritus of the University at Buffalo School of Medicine and Roswell Park Cancer Institute and past president of the society of head and neck surgeons. Dr. Shedd with one of the founding members of the board of hospice Buffalo.

[00:01:56] Today Dr. Milch and Shedd discussed the history of hospice and hospice in Buffalo the challenges of the early days of hospice changes that have developed over the years and the nature of care and what they see as the future of hospice and palliative care. Dr. Deborah Waldrop associate professor at the University at Buffalo School of Social Work interviewed Dr. Milch and Shedd. Dr. Deborah Waldrop from the University of Buffalo School of Social Work and I have the privilege today of speaking with Dr. Donald Shedd and Dr. Bob Milch both of whom have been central figures in the hospice movement in Buffalo as well as regionally and nationally. We are grateful to have the opportunity to be able to record how the history of hospice and hospice Buffalo shaped current care for people who are dying and how they believe that hospice care will evolve in the future. I'd like to begin by asking our guests to introduce themselves and just give us a brief explanation of their work with hospice patients and doctors should have done. A retired surgeon from Rosewell Park Cancer Institute and I was born my wife in the early days of hospice Buffalo. Bob Milch the emergency medical director of a hospice buffalo. I've had the privilege of being associated since 1978. Thanks very much to both of you for being here and for sharing your wisdom and your expertise and your experience with the hospice movement and the evolution of hospice buffalo. We really appreciate it. I'd like to begin by asking Dr. Shedd to give us some of the history of hospice Buffalo. And so my first question to you would really be what is the original germ of the idea for starting a hospice here in Buffalo. Could it ever in the late 1960s my wife Charlotte and I working at a university. She was a nurse and I was a surgeon.

[00:03:48] We both were impressed by that term the level of care provided to terminal cancer patients. At that time the emphasis was on the cure of disease but there was little interest in providing good cooperation. The patient could not be cured. There are other came to lecture here one woman Cicely Saunders from London who was the founder of the modern hospice. She was a person who had undergone training as a physician as a nurse and was a social worker. We're very impressed to learn from her that it was possible to the what is a terminal cancer patient a much higher quality of care was the norm in the United States. This involved caring for realms the physical psychological social and the spiritual with these components being provided by an integrated team of individuals removed from new to Buffalo in 1967 with the concepts of Dr. Saunders lodged in our brains while serving on the board of both the Visiting Nurses Association.

She came into contact with a nurse from the University of Buffalo faculty are reading my heart who also had an interest in the hospice council. They put their hands together and decided to explore the possibility of hospice care in our city. That initial board was formed composed of the following individuals Ralph Lowell pastor of Holy Trinity Lutheran Church Charles Buckland spring Dropcam Hattery County Medical Center Father Eugene Olbrich a Roman Catholic priest. Hard work toward Jerusalem. Among them are remote more Harthorne nursing homes and Sherlin serving as church person and I was six months working at the time as a surgical oncologist at Rosewell Park Institue. Wow.

[00:05:38] She really brought a lot of visionaries together and really learned from Dr. Saunders To begin with and then from local visionaries to get her to really get this started. That's impressive what were the early steps that you all took to get started this group many times and gradually organize a strategy to develop the idea of a unit in Buffalo. The biggest part of the task was to educate the public and the professionals about the basic concept a number of informational meetings around during the message to various groups. Gradually things began to fall into place with an early important tradition being the participation of a young surgeon Dr. Robert Milch. His presence went must serve a degree of medical respectability to the project. It's wonderful to have both of you here to tell the story and that's really terrific. I'm certain there must have been obstacles that you ever came to get underway but could you tell us what those obstacles are. What were the first quarter. There was no real interest in making any changes in the manner of caring for patients with terminal illness cycle. It was difficult for the authorities to find a place to fit this new concept into the overall structure of health care. I remember one incident from early days when Charlotte went to the state capital Albany. The concept of some of the state health authorities after a presentation of those experts the response was ready why don't you go to Buffalo and take your Lucho room and let us in on this. Health care needs of New York State. The third obstacle was a difficulty in funding for this innovation of medical care.

[00:07:21] When foundation Buffalo took a chance and did provide assistance in those early days and then gradually more definitive sources of support came online just a testament to her championing of this idea and her perseverance and how important that that really was in getting started. With support from the community along the way. There are a surprising number of people in the community who recognize the need for better term care and many of these volunteer their help in various capacities. Was Charlotte active in the hospice movement beyond buffalo. At that time it was occurring at the national level was impressive. Across the country another hospice units were getting off the ground and individuals involved in the movement formed the National Hospice organization in order to provide information on how to solve the many problems that the movement faced. And served as treasurer of the national organization. Gradually some of the units organized to porn or they could offer care to patients and modern hospice cancer got underway with the movement in turn becoming a major enterprise. It is today so I'm wondering then Dr. Milch if you could share with us what the nature of hospice care was at the time you came in joining hands in the beginning. It was very much a volunteer and frenetic service that bears little resemblance to the programs of today reflecting on the questions you ask Dr. Shedd. We served as a demonstration project in New York State for hospice care. That's a testament to what Charlotte was able to accomplish just with limited resources.

[00:09:12] But in 1982 the federal Medicare benefit was crafted which was a lifeline for us because it provided a steady source now of reimbursement which we did not enjoy up to that point and we had been given care for five years then dependent on the generosity of the community and bequests from patients and families that benefit turned out to be a two edged sword. Perhaps some shared some of this story before but how we got the notion of six months or less that's defining the Medicare benefit really came from David Stockman who was the man chief at the Office of Management and Budget. And when they were crafting the benefit they came to Mr. Stockman and

said well if we had X number of people theoretically who could be covered by the benefit and Y amount of money allocated for it. How long can we afford to pay for it he said. Six months ago US and so the defining part of the hospice Medicare benefit of six months or less comes from an actuarial and has no clinical relevance says we all know to service that's provided that notwithstanding it was a guest at that time. It's such an interesting juxtaposition because I know now the Medicare Hospice Benefit is often seen as a barrier. The six month rule is often seen as a barrier to appropriate timing of hospice care. Certainly conceptually it is for a whole slew of rational and irrational reasons. As I say to its interesting thank you. So how has hospice care changed since that time. I think you really were there during the volunteer era and then you saw the change from the Medicare hospice benefit somehow. What are the major changes that have accompanied that process.

[00:11:14] It is certainly organizationally the use of an interdisciplinary team physician directed nurse coordinated utilizing the services of professionals in social work in chaplaincy and counseling and even in the organization of volunteers that has brought a degree of coordination and rationality to the care which is offered. We've also expanded our VISTAs far beyond those of strictly taking care of the patient with cancer recognizing this palliative and hospice care is appropriate for patients who are approaching the end of their lives they should not be diagnostically restrictive component to it. And so we presently take care of patients who have heart and lung neurologic disease than we do patients who have cancer and their trajectories are different than their ways of dying or difference imagine that that really shapes and has influenced the delivery of care at the end of life. Absolutely the nature of care has become much more sophisticated. Demands for understanding the different therapies far more complex and involved reliance on the smooth working of the interdisciplinary team much more crucial from the way it was let's say 25 years ago. But that's also been the fun of it is to change with the changing needs and to see that we're able to bring a slew of skills across the professions to bear as needs have changed. One of the other dramatic changes that I've seen and you've lived is the advent of new environments for hospice care. Now hospice is not only to live in the home as it was in the beginning Charlotte was beginning this movement I'm wondering if you can talk a little bit about the different environments for hospice care and how they've come to be. We wanted our program to be able to meet the needs of patients and families wherever they were.

[00:13:23] So while we began as a home based service we used to rapidly develop liaisons with the hospitals in western New York so that we could have acute care services for patients who needed it for symptom management or patients who could no longer be safely cared for in their own homes. We rapidly identified and the needs of patients particularly the frail elderly who could not be cared for in their own homes and so establish far reaching programs with skilled nursing facilities in the community and at the present time of contractual arrangements with more than 25 of them so that we could care for those patients in that population as well. We also developed the concept of the residence Hospice Residence which is fundamentally assisted living for people who would otherwise have to be in nursing homes. People who can't live by themselves in a safe environment for example and we find in that patient population longer lengths stay very often. We do patients who otherwise would have to be at home or institutionalized elsewhere. We've also expanded the capabilities for acute care services are inpatient unit here in Cheektowaga and a number of hospice beds in hospitals across the region so that with the exception of the Roswell Park we have hospice affiliated beds in every hospital in western New York. It's amazing to hear how much and how comprehensive it is. I know it hasn't always been like that. Wondering and I think when you think back about the movement and how it came to be how hospice Buffalo ended up at this location. And I know there's a story that goes along with that the different locations and wondering if you could share with us.

[00:15:32] Well some of the places were along the way that hospice was now. We've wandered

quite a bit. Actually we started in Charlotte Stein the detail and that's significant because of the mutual support that the Founders had with one another and starting to set foot out in the community I think was critical. And then the officers of course moved from 29 to 9 Main Street which was the second floor of the loft of Pollock paint factory as I recall right next to Ohio Stadium. It was a creaky steps. And from there temporarily out the north campus or near the North Campus of the university and then in 1990 beginning a capital campaign to acquire 21 acres as part of the Reinstein nature preserve which is art. Our present home. Wow what a story it really is just so interesting to see the whole developmental Valvis. So in your experience as a hospice physician you have worked in all these environments and you've worked throughout the history. I'm wondering what are the greatest challenges that you face. You see people at the bedside you see the organizational issues in the national picture what it means challenging the daily basis all the above. Actually I think it depends almost on a given day the challenges of meeting the needs of patients and families in their homes. This still is the bedrock of hospice care. Everything else needs to be in service to the concept of patient care. The challenges of locating that care elsewhere in hospitals and acute care settings in residences or nursing homes. Each brings its own set of challenge whether it's the negotiations or the actual care delivery.

[00:17:39] The challenges of team support and for physicians who very often are told headstrong and Kitto the captain of the ship sort of mentality. Learning to function as part of an interdisciplinary team where primacy is assumed by the professional for whom the patient family have the greatest needs at any moment in time. It may be that the physical symptoms are well controlled and the doctor thing has been taken care of but we need the counseling that comes first from the social worker perhaps or from the chaplain or perhaps her needs in the home where we need a child life specialists to work with the children of patients and younger members of the family constellation learning to do that is a process and can be a challenge. Now one of the other challenges I think is trying to facilitate the utilization and incorporation of hospice and palliative care into the mainstream of healthcare delivery. Certainly starting with education starting in the schools medical school nursing school School of Social Work. And I'm glad to say We have cordial relations with them within the educational community working with our colleagues in medicine to perhaps sensitize them to the utility of these supportive services for patients who have IWAY symptomatic of chronic and progressive illnesses and to be able to provide palliative care and hospice services across the continuum in patients lives that can be challenging and certainly this is done on an ever changing landscape and wondering how similar or different than those challenges are nationally. Seems you know you've had experience recently here. I'm thinking it's probably very similar to physicians out there. Yes and No actually I perhaps ethnocentric quit tried to keep our focus local and regional.

[00:20:05] And while the national cudos which followed were heartwarming to see and I think reflected a part of the sophistication of our program as it was developing. There are differences between what we have been able to do and some of the challenges of other programs face for example we as part of a certificate of need state are the only Hospice in Erie County in the city of Houston. There are 35 hospices and by virtue of the competition if you will that has been set up many of them are not able to offer the scope of services which we've been able to offer here perhaps like keeping Oh it goes back to Robert Browning You know a man's reach should exceed his grasp of Ellsworth's for and trying not to overreach but to remain pertinent to the needs of our community. In all these challenges I'm sure there are rewards is long and wondering if you could talk a little bit about what that's like for you. Three words are being a disposition levels. Certainly the professional level knowing that you help patients achieve the level of physical comfort and control of that aspect of their disease and illness is always rewarding. But I think the opportunity to revert to the pastoral role which physicians used to use to have perhaps in more abundance that we see are charged to be. Now is personally rewarding. Tell the students and the residents when we hear specially why you're doing hospice care. Isn't that depressing.

[00:22:05] You know the first challenge is to redefine a good outcome and to work with patients and families to set the bar as to what they would consider to be a good outcome and if you can meet those expectations and those hopes for patients and families well there's nothing more rewarding to do a physician. The other reward comes from working with colleagues across multiple disciplines and to be able to see the degree of facility that they bring to their professions and their interactions with patients and families. It's like your said shares a feeling that I have. You know when you've seen great surgeon work you know when you see a good operation. Well when I see how my colleagues work and what happens when a chaplain or a social worker has had the opportunity to help with resolution of distressing symptoms that's a little bit of magic to take a good word for it. Thank you for that. So in the end we've heard the history of this moment we've heard the history of this incredible organization that's now you know to come to full comprehensive nature of hospice care. I'm wondering if you think that the past predicts the future and in any way what your vision of what will be coming will be for either of you that would be willing to share your thoughts about what the future holds for hospice and palliative care. My hope was already mentioned the total absorption hospice concept in the mainstream of care or something. So it's a household word in everyday world of things national uncategorized it's everywhere woven into the fabric and I think I think we're getting there over time. We now care for 40 percent of the people who die from illness in Erie County every year. I dare say that speaks to one way or another becoming more mainstream.

[00:24:17] I think our challenge is going to be to maintain our dexterity our willingness to to study our environment our fellow citizens needs and craft innovative programs that still are true to the tenets of palliative care hospice care and meet those needs challenging a changing environment in this era of health care reform. Doing so in a fiscally manageable way is always also a challenge and it gets absolutely ghastly moving target. Thank you very much Dr. Shedd and Dr. Milch for sharing your experiences and your expertise in hospice care and for your wisdom about the needs of people who are dying and their families we are greatly appreciative of having this in our series. Thanks so much today. Thank you. Deborah you've been listening to Dr Donald Shedd and Robert Milch discuss the history of hospice buffalo. Thanks for listening. And join us again next time for more lectures and conversations on social work practice and research. Hi I'm Nancy Smyth professor and dean at the University of Buffalo School of Social Work. Thanks for listening to our podcast. For 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.