Episode 217 – Kimberly Washington: Theraputic Patient Navigation: Filling the Gaps for Clients with Neurodegenerative Disorders

[00:00:08] Welcome to inSocialWork. The podcast series of the University of Buffalo School of Social Work at www.inSocialWork.org. We're glad you could join us today. The purpose of inSocialWork is to engage practitioners and researchers in lifelong learning and promote research to practice and practice to research. We educate. We connect. We care. We're inSocialWork.

[00:00:38] Hi from Buffalo Buffalo and western New York has invested significantly in our bike culture and cycling opportunities. You can roll along our lake and river fronts from our harbor to canalside downtown continue through front park along the Niagara River and maybe end up on Niagara Street where all sorts of food and drink distractions await whether you write for fun race do a slow roll through one of our neighborhoods with 100 bicyclists or join a club. There are a surplus of opportunities to get out and pedal around. I'm Peter Sobota in this episode, Our guest Kimberly Washington discusses Catholic Charities St. Jude's Project in Washington D.C. created to serve those with neurodegenerative disorders explaining its grounding into evidence based models. Ms Washington describes how this intervention was formed to fill the gaps between the services that support patients with diseases like Parkinson's Huntington's and Alzheimer's. Speaking to the many social work role she and her colleagues fill varying depending on the needs of each client Ms Washington identifies how the St. Jude's project is able to provide wraparound services. In closing she discusses the next steps for her and her team Kimberly Washington LICSW LCSW is program clinical manager for the St. Jude's project at Catholic Charities in Washington D.C. Ms Washington was interviewed in February of 2017 by our own Dr. Louanne Bakk clinical assistant professor here at the School of Social Work and soon to be cohost of the inSocialWork podcast

[00:02:28] Kimberly, I wonder if you could tell me about your current project I'm so interested to hear a little bit more about the St. Jude's project.

[00:02:35] OK thank you Dr. Bakk. This story around the project starts well before the actual project. So I want to start with that some time ago. Our funder Mr. Jack Griffin found that when his family members was acting uncharacteristically and he supported her through getting help and trying to find out subsequently she was misdiagnosed several times before they found out that she had Huntington's disease. So he is a man that has considerable resources but still found that it was very difficult to find individuals who would help him with this particular illness and overall help him navigate what they should do next. He's a very industrious man. So he went to one of the local universities found a neuropsychiatrist is there brought her to Georgetown and created the H.D. Huntington's Disease Center at Georgetown. After some time he found that there was still some patients being underserved in the community who needed an extension of what the hospitals were providing in terms of case management and so forth. So he came to Catholic Charities and asked us to start a program that would reach out into the community and serve those patients. That's when the St. Jude project was created and it was created to serve patients in response to the lack of community support for patients with neurodegenerative illnesses.

[00:04:04] Fascinating. Yeah such a need to it sounds like. So I know you mentioned the underserved populations but was there any other impetus in regards to why the St. Jude's program was created besides what you talked to me about already.

[00:04:16] I know you have some work with disparities in access to different parts of healthcare and things like that. I think when you're talking about patients with neurodegenerative illnesses it's generally poor long illness. So from start to finish there are so many different aspects of this illness that really require comprehensive help and that doesn't exist in any form for this patient population.

So really as we got to you know acting with these patients understood more and more that the program was much more needed. We had anticipated.

[00:04:52] So you saw much more of an outcry for that service once you actually had it in place

A bsolutely because what was happening is when you're talking about something like Huntington's Parkinson's multiple sclerosis HLS I think there are so many more moving parts. The medical team could include a neuropsychiatrist a nutritionist a physical therapist movement person. It's a large team. So if you look at that in comparison to perhaps diabetes cancer some chronic illnesses. Everyone I think in the general population understands what it means to have those illnesses and then it's not as complicated a team or complex y variety of individuals involved in helping you maintain your health I say.

[00:05:40] So as you think about this. Was there a specific need for social work with this population.

[00:05:46] I think so. One of the aspects of taking on a sick role in your life. We think about how you go to the doctor and get this diagnosis and you think about well what do I do next. Do I need to go to a specialist. How long will I have to live. Will I be able to work anymore. It's a variety of questions that come not only into the patient's mind but into the family and caregivers. So everything for them might change just that quickly with a diagnosis of neurodegenerative illness is their home appropriately outfitted for the progression of their illness will they have to be in long term care. So as you can imagine the emotional stress of having an illness like that is not only for the patient for their family. And it impacts the family in ways you couldn't imagine. And there some of these individuals who are older in age and some who are younger and who have children and they want to see those children grow up and how do they provide for their children with the illness like this. So as you can imagine the need for the therapeutic piece of our social work was great supporting these individuals helping them through the adjustment phase understanding that they are grieving their old life things like that.

[00:07:03] As you know I've done some work with the older population and you did mention age as being one of the populations that are impacted with this disorder but across other disorders are older adults for example dementia Alzheimer's once they receive that diagnosis it can drastically changed things and I'm not of what you're mentioning that you do need to make sure that people are equipped to move forward the best they can with their caregivers.

[00:07:26] As you can imagine Dr. Bakk just one aspect of the emotional adjustment if the person that has that illness or their family members are in denial or lack the awareness around what they need to do. And there is that lag time of them addressing this through some kind of medical team. Sometimes the symptoms can progress even more quickly than if they were at least have some medication to address the symptoms have some appropriate physical activity or different therapies that would help them. That's just one aspect. Being in denial have that lacking that awareness around the fact that there needs to be some sort of care plan. Can we just one snag an aspect of the need for social work that have that professional come in and use some therapeutic tools to help you address the underlying issue around your denial.

[00:08:22] Kimberly what does the St. Jude project provide to patients with these disorders.

[00:08:28] Generally we provide something that's community based patient centered collaborative therapeutic and comprehensive. So under that in that community based heading of what we do we go to the home care. We go into community. We go to a doctor's appointment. We go to the grocery store. We go to the pharmacy wherever that patient might need our support. We go there and as a social worker I'm a firm believer that there's nothing like having eyes on patient and family in their community where they are and many things don't come up until you arrive. For instance I was going to do a home visit with a patient. Her family was there. On this occasion she got up to go to the bathroom and then they unleashed all of these issues that they had and that they were concerned about and said you know have you ever spoken to the patient about it. No we haven't talked to her yet. So my presence alone as a therapist gave them the opportunity to really really open up about some of the issues and concerns that they were having that really needed to be talked about in a safe setting. Many many other environments that were in the doctor's office for instance oftentimes if you have a patient and they have cognitive issues even for the most able bodied person you go to a doctor you don't always understand everything that they're saying. But the Times asked for clarity and so forth. However without mental issues and you go to the doctor and you have questions but you processing isn't as fast. So the doctor isn't aware of that and they rattle off what should do and is everything OK and that sort of thing. I've gone with patients and patients said Should I take this medication and a doctor went into a philosophical why doctors like this medication and generally what it does and this and that both sat there quietly and I interjected at the end. Should she take the medication and then she said Oh absolutely. If it helps. Medical profession so improved as they are in terms of trying to communicate to patients many times patients leave with a discharge or summary of that visit not understanding everything that they should do it often impacts their ability to follow through with the plan.

[00:10:42] Absolutely. Absolutely. I mean just my work with the aging is much the same of what you're saying. And oftentimes their time is so so short with a patient as well. In addition to everything you're talking about giving all those orders in the patient doesn't always have that opportunity to ask questions or they don't think what to ask or they don't understand but might be reluctant even to ask them. That's something that I found particularly with the aging population

[00:11:09] Absolutely we're in a managed care time of our lives. And this means that doctors have a certain amount of patients they need to see. I firmly believe that they want to provide good service to patients. But when you have a certain amount of education the way you talk in the way the patient speaks about things medically may not be the same. I've noticed that patients may need to break it down a little bit help them understand the consequences of what's going on. I know I met with a patient and she had her point met the neurologist and we sat outside of the hospital on the bench while she explained to me that she had gone all the way down the road in her mind that if the doctor said a certain outcome was going to happen she was going to have to leave her current housing and none of this was the case. But she had really wrapped herself up and gotten frightened. So how much do you think she really could hear of that appointment while she's sitting there frightened and then she was listing those key words that meant she would have to leave her housing. And so we were able to unpack that and go through and reality check and do some cognitive thinking around what was really going on was she she really expect. And I find that these patients really need that and really acknowledge the support and how believe they are when we can go to these appointments with them.

[00:12:30] Absolutely. What did you and your staff find was unique about working with patients with this disorder

[00:12:38] All of what I just explained makes these cases very complex. So from beginning to end you made me a patient who was recently diagnosed. Have they found a specialty facility where they can access the right kind of care for their particular illness. Do they have supports in place in the community natural support. Do they have the financial resources insurance that will pay for most of what they need. Do they need to apply for SSDI do. We meet them in the middle of the process where they're starting to show serious signs of their illness. Becoming a parent that they can't drive anymore or they can't maneuver their home anymore. What do they do. Are they going to go to an assisted living or are they going to have long term care facility. Or we may meet them towards the end of their lives where they're in a long term facility and their time is short and helping the family determine what's the best route or you know helping them acknowledge and accept the fact that their family member appears to be in transition of their life. We could meet a person on any part of that spectrum and then all of the factors surrounding that time for them such as the support the financial issues whether they want to have a will or do they need legal help. Those things require that we have consistent often assessments of each patient that we meet and continue to work with under a normal social work model you would assess once a year and every time you see that patient you're looking for what's change what the needs are so that you can continue to meet their needs wherever they are.

[00:14:24] Sounds multifaceted. It seems like it's continuing evaluation and re-evaluation.

[00:14:29] Absolutely. You've hit it on the head.

[00:14:32] Were there any gaps in patient care.

[00:14:34] As I said one aspect of it is when you have illnesses that are rare or tends to be less medical news sources and then community social services. So obviously something that's not as common. You can't find a doctor that specializes in it. You have to travel long distances to go to that doctor. Things like that whereas if you have something more common there may be a doctor right down the street that treats that illness lack of resources. Also calls disparities with these patients. If you're one of those patients who don't qualify for the Medicaid waiver program you would maybe pay for a lot of different things you may need to stay in the home and so forth. Then you're looking to pay for those out of pocket while you're on SSDI. So you make just a little bit too much to qualify for that right. But you still need someone in the home you still need transportation places you still need food. Those kinds of things present huge gaps in care for a certain part of the population who don't have the right resources. Really these programs are state by state. I work in the Maryland Virginia D.C. area right now. And so the counties that these individuals are in or Outside of D.C. makes a big difference in terms of what they offer through the Office of Aging and Disability that might be in that area. There are of variances between states and between areas within the state in regards to qualifying and what the cost is that someone will need to pay. Another thing I found just in working with the waiver is depending on where you live there can be a longer wait list so it. My goodness. Yes the wait lists and the individuals to coordinate the care is just so lengthy. And I think they tried to clean this up in the last few years but it really does take a lot of paperwork and follow up that if you're sick and sitting somewhere and don't have individuals working with you. How are you going to complete those tasks locally. I work with the D.C. Office on Aging and they have been working for years to really really make sure that the system that they have in place is streamlined because they know that many people have been on these waiting lists for many years. And the program can only be effective if there is some internal external and community follow up to all the different parts that are required for patients to get on the program get assessed and receive those services in the home.

[00:17:11] we've talked about some of the uniqueness of working with this population and gaps. As you Think about the population how did those distinctions in this population lead you to explore the expanded model of care

[00:17:23] When you're thinking about patients with neurodegenerative illness is it really the assessment and collaboration part of the model became really expansive. We had to collaborate with so many different people so many different community organizations and partners to get what each patient might need. So any given day you might be working with the hospital you might be working with a local community organization that provides transportation or caregivers. So you know you generally you're working with the medical teams benefits home support community organizations and of course the patient and the caregivers. So it all has to be patient centered based on what the patient needs. I think it becomes really really important to focus on those two issues assessing and then coordination and collaboration. From what you find the needs of the patient are as a social worker you want to make a few calls get these things in place for the patient and then kind of follow up on whether there was follow through and how it all worked out however. You know when there's so many people involved just the lack of return call from one organization can stall the process in a way that is damaging to your client. And then sometimes there just isn't the level of responsiveness that you would like. That's where your social work skills come into place. And I find that you just have to be tenacious and make sure that these patients get what they need. All of those different parts of course as a team we have to be organized and then you know all the different people were following up with. We have to develop the kind of relationships with them that are exchanges and that they feel like it is beneficial for them to respond.

[00:19:13] Yes. And one thing you're mentioning as well it's the individual in the home that's receiving those services. Often times they have a hard time tracking who's coming in and who are who's not coming in.

[00:19:24] Exactly. I think that's part of the uniqueness of this program is that it focuses on caregivers as well. Call to you how it was for me to go to a home where I have previously met with the identified patient but a whole new world of information was provided to me by her family. She lags a lot of the awareness because she has medications and things like that and she feels like everything is OK but unfortunately you know the family was able to say these are some additional issues that are going on. So it's hard sometimes for a patient to see all the problem areas first and foremost but also have all the energy and follow through that they need to sign the paperwork make sure it gets mailed. Make sure it's back to the right person call to make sure things have been followed through. I don't think you can expect a patient who has a serious illness their symptoms are progressing to really manage all that I think it would be difficult for anyone to

[00:20:24] How did Research on the evidence on patient navigation and care inform them the way that you went about providing comprehensive social work to the US population.

[00:20:31] We launched December of 2015. So prior to our launch it was my mandate to sit down and figure out how to provide services for patients. We started researching and trying to figure out what model might look best. St. Jude sits under the Catholic Charities Archdiocese of D.C.. So Catholic Charities D.C. has a long history of providing wraparound services and different types of services. So of course we wanted to incorporate what we already knew but as I started to research I came across a patient navigation which was a natural fit but patient navigation which was created by Harold Freeman in the 80s to address disparities in cancer patients of color primarily African-American and Latino patients in order to help them get greater access to care and then also manage their care better. So patient navigation in that sense was not going to be enough to really manage what we were doing with neurodegenerative illnesses. What we decided was that we needed patient navigation. What looked like patient navigation and wraparound services which came out of Alaska in the 80s to deal with youth who were struggling with challenging behaviors they had to work in wraparound services with the family to get these children into care that would help them visually go back into the community. So we put these to evidence based models together and call it therapeutic patient navigation. So evidence based practice had everything to do with how we set up model of care. Two very successful programs that dealt with some kind as sibilance of our population but not the population because what we've found is there was nothing in terms of a social work model that looked like what we needed to

[00:22:28] I see parts of this actually laid the foundation for the model moving forward.

[00:22:32] It gave us the framework and course we had to adjust because what we were doing was now out in the community but in different public institutions working collaboratively. So we were bringing so many different pieces together. No one model represented it and we really had to create something. It just became more and more obvious.

[00:22:52] What are your program goals.

[00:22:54] Well first and foremost just to frame it most outcomes with regard to health programs or patient programs look to improve the patient's health with progressive illnesses like Huntington's and Parkinson's and such. Is no way to do that. These illnesses are going to come along and go in the direction of probably more symptomatic and then end of life. So we knew that that could be the outcomes for us so the goal is for us the foundation of our relationship with the client as a therapeutic relationship. So we base our most important goal on therapeutic alliance. We want to make sure that the patient feels support it and that they feel hurt and that they feel like they have someone to walk through their health journey with.

[00:23:41] How do you go about measuring this.

[00:23:43] We use surveys. We check in with the client on a regular basis. Is everything okay. Even after each session. Sometimes I'll speak with the client and say did our session today make sense. Was it helpful. And then quarterly. We give surveys to make sure that the clients feel comfortable that they feel supportive and that you know we're doing a good therapeutic job with that. And that speaks to our another goal that we have is secondary goal is to provide each patient with supportive interventions pertaining to this care. We don't just go have therapy with them obviously we do Case Manager treat dodging and things like that. So like you said with their providers and such we make sure that we've implemented some interventions that help them maintain their care or plan their care or different aspects of their illness care. So that's another central goal that we have. And and we generally measure that by taking a look at our database to see what kind of services we provided and making sure that 80 percent of our patients have received some sort of intervention from us.

[00:24:51] How will you follow up on the effectiveness of this program model.

[00:24:55] Well we're looking for people like yourself Dr. Bakk and other researchers and organizations who might partner with us in the future to help us design a research tool that might measure what seems to be to some nebulous the therapeutic quality of life that this person feels. I think researchers want firm numbers of whether you know the patient improving care and such but for these type of social work models that are patient centered and quality of life wellness models. We're trying to do some research and partnering with some organizations that might be willing to help us. You know some of the other outcomes we're looking at are whether these patients have easy access to accurate and understandable information about their illness. Some receive emotional and practical support through their choices and the team involvement because I think I've had a situation recently in which I visited a matriarch of the family who has several daughters with Huntington's disease and she just knows nothing about Huntington's that's a great source of anxiety for her because she feels that she can't care for her daughters if she doesn't know anything about the illness. And so I think we feel like we need someone with the illness they already know with illnesses about educating and making sure that if she doesn't have a computer you know if we need to sit down and just talk with her and go over some of the aspects of the illness these things are really important. Also I feel like to the extent that we can help the patients with feeling good about symptom management whether they've been able to access our doctor who can help them with proper medications and the right protocols to help them with their symptoms we know they're not going to go away. But for instance the Koreas a movement aspect of Huntington's disease. There is medication for that. And we've met patients who hadn't accessed that yet and we were able to help facilitate that. So these things speak directly to you know their health and well-being and quality of life. When you know they can keep these kind of things under control to the best of their age.

[00:27:11] Absolutely. I know that I did a project a couple of years back where we talked to care partners and individuals with dementia and met with one of the primary things I heard I heard you mention education but knowing more about the disorder knowing more about patient care as the illness Progress's for a couple of our top needs that we found under this.

[00:27:32] And when you meet the patients and families say with Huntington's because it's been a rare disease over the years they know more about Huntington's what's coming down the pike in terms of research and disease. And we'll meet patients and families who are great advocates for themselves. And it's wonderful to see that there are some patients who can gain access to that information but they really have had to and they have really no other choice because there wasn't a lot of information out there. Now there's the Huntington's Disease Society of America and different organizations HD centers all around the U.S. globally. There's lots of information to access. But as a rule I think that you know understanding what impacts health. And then you know being able to focus on the greatest needs and collaborating to maximize what you can get out of community and resources. I think you know first and foremost it starts with being educated.

[00:28:38] Absolutely. And I found just some of my own work too as we talk about education. There's a plethora of information on the Internet but we always can't assume that people have access to a computer nor have the time to navigate and find the information. I might add.

[00:28:55] Absolutely. You're correct in that you know our aging population is less tech savvy in some instances and is reticent about getting on the computer and the Internet. And you know that's frightening to them and you can also add a lot of these patients who have cognitive issues. One of my patients for months come to her house and help her reset or find her password. We write it down. We've finally figured out a system to write down her password. But she would lock herself out of that computer regularly. It was her processing speed their incompatibility that allowed her to really use the computer in that way. So when we're dealing with practitioners that she interacts with I have them e-mail me important forms that are printed out. When I see her weekly I give her the forms. So as you can imagine asking a person like that to try to just go on the internet and look up HD you'll see a lot of information. I took another patient the actual piece of paper on her Parkinson's she had a lot of different symptoms that pointed to her Parkinson's but she would say due to my old age I'm going through these issues. And so we had some denial in the beginning and when I gave her the papers on Parkinson's she promptly the next session threw it back at me and said I don't know what that means. And so obviously a part of it was still her denial. But I had to walk through that paperwork with her and sit and explain to her. You said you had this symptom last week and you see it's on the list of symptoms for Parkinson's. You said you had the next symptom. And so we went over it slowly and it took her maybe seven months but she finally would acknowledge her Parkinson's and do exactly what the medical team reminded her to do. And we even go on walk during our sessions because movement is one of the primary tools that help Parkinson's. So during our walk we walk through the neighborhood talk over everything and then we end at a bench somewhere and she has paperwork to give me or things she wants to show me. But that's a part of our social work practice is to walk during that session to model what behavior she needs to continue on through the rest of the week. So you have to bring information to the clients and the way that they understand and can utilize because you know it is a great idea. Never a great idea unless someone can really use it.

[00:31:11] How old are your patients responded to the social work model.

[00:31:15] I think they have welcomed with open arms. Many of them did not want to focus on having a social worker help them but they were able to utilize that care. They found that it was just so relieving to have someone to talk to. First of all someone who understood the illness and the impact that it could have on them and their family may times they actually just need us they need us to help them with issues and challenges that they may be having. So you know they're very happy and relieved to have that help to really unpack what's going on. How should they go about planning things like that and to also access that care and the services in the community. Many times they just don't know where to start. And you know we walk through that with them. And so far we've had really good results on the surveys. You know always adjusting to when certain things don't work as well. Making sure that we follow the directions of the patients what they need.

[00:32:14] So one of the closing questions I want to ask anything else that's next for you with us program.

[00:32:21] Well I think I had a steering committee meeting probably this week and you know we're really going to try to publish have an article in the new social online social work magazine about patient centered care but we really want to take this model and put it out there to peer review so that we can get that critique back and make it into a model that others may be able to utilize if they're serving this population.

[00:32:46] It's a great idea

[00:32:48] About me sitting down and making sure that I have the time and you know collaborate with some others at the agency and to make sure this happens. And then of course the further branding of the program so that whoever needs to utilize it can do so. And you know it is a grant funded program through the Griffon Foundation the funder wants us to think outside the box to innovate. And so that's given us great freedom to kind of explore what is the scope of our social work practice. What is evidence based and how to bring those two together who push it. Push the mind a little bit further. You know we want to make sure that this program has some sustainability financially through you know gaining more grants and finding ways to collaborate with other partners to contribute as well

[00:33:34] I definitely encourage you to get it out there as far as publishing because it is a little bit different model. You mentioned you looked at some of the evidence and developed your own model of terror. So I think it's it's really critical.

[00:33:45] I think it's coming. We had been operating just over a year but you know it's been exciting and really refreshing because I feel like this is what I went to social work school to do to work with patients in a way that's meaningful. It's not always going to be meaningful and making it better and they're going to live forever. But it is meaningful when you see the look of relief on individuals faces when you arrive and they can talk to you about things that are really really concerning them and you have them some answers for them or you help them work it out really been an exciting program for me to to launch and as the clinical manager of this program you know really sink my teeth into so many different aspects of you know how it runs the outreach the branding and direct service. You rarely get the opportunity to do all those things in one position. Busy days. But does

[00:34:43] But it sounds very rewarding.

[00:34:46] Absolutely.

[00:34:47] Anything else you'd like to add.

[00:34:49] No I think you know I've enjoyed talking to you and I really appreciate the work you've done. I have a real passion for the aging population.

[00:34:56] Kimberly it was such a pleasure to talk with you. I mean you've done some fantastic work with the program and I congratulate you on the work that you've done.

[00:35:04] Thank you so much for taking the time to speak with me today.

[00:35:07] Thank you.

[00:35:08] You've been listening to Kimberly Washington describe neurodegenerative disorders on inSocialWork.

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