

Episode 22 - Dr. Lori Wiener: Children with HIV/AIDS: Issues Of Survival, Disclosure, and Transition

[00:00:08] Welcome to living through 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. The University of Buffalo School of Social Work is celebrating 75 years of transforming lives and communities. We would like to invite you to be part of the celebration. Please visit our website www.socialwork.buffalo.edu to see a full list of events marking our seventy fifth year leading up to the gala celebration. I'm your host Oduor Robinson. Today's podcast creates a discussion with Dr. Lori Wiener. Dr. Wiener is a researcher and a clinician she is the coordinator of pediatric psychological research program in the pediatric oncology branch of the National Cancer Institute. She has dedicated her career to the field of oncology and pediatric HIV AIDS. Dr. Wiener received her Ph.D. in social work from New York University and held a private practice. While working at Memorial Sloan Kettering Cancer Center Dr. Wiener's clinical research has focused on parental needs and coping children's distress diagnosis disclosure loss and bereavement and interventions designed to meet the needs of critically ill children and their families. She also brings with her a wealth of information about the inner world of medically challenged children some of which have been published in a book entitled *Be a Friend and Alphabet* about families living with HIV AIDS workbooks for children living with life threatening diseases and a therapeutic board game called *shoptalk*.

[00:02:04] She has just completed editing a reference book entitled *Quick Reference for Pediatric Oncology Clinicians: Psychiatric and Psychological Dimensions of Pediatric Cancer Symptom Management*. Today Dr. Wiener discusses how her work with gay men. At the beginning of the AIDS epidemic informed her work with children with HIV AIDS and how her research agenda is shaped by the needs of her clients particularly with regard to disclosing one's HIV status. Dr. Robert Keefe, associate professor at the University of Buffalo School of Social Work spoke with Dr. Wiener. Lori Wiener thank you very much for joining us today. My pleasure. Dr. Wiener I know you have been working in the area of HIV for a number of years. Can you tell our listeners how you became interested in the topic of HIV. Oh it's a very interesting story I actually didn't become interested in the topic of HIV. I was in New York City in the early 80s when the disease was first becoming known as gay related immune deficiency. And so it wasn't something that I had chosen as an area of specialties. Rather it was the place that I was at the time and an emerging epidemic. I know your dissertation focused on HIV and I believe you did do a lot of work with gay men at the time which led me to question much of your current research now focuses largely on children. How did you switch from looking at gay men to children with HIV. When I first began in the field we didn't even know children could become infected at the time.

[00:03:49] It was again it was it was thought of as being gay related disease back in the early 80s. And I ended up developing one of the first psychosocial support programs for persons living with AIDS related to the deficiency in New York City. Within the next few years it became apparent that this was a virus and that it was not only gay men who were infected with this virus but indeed it was anyone who was at risk. And a few years later in 1985 I moved down to the Washington area and took a position to be able to help incorporate pediatric HIV into an existing pediatric oncology program. Throughout the time that I was at Memorial it became the gate disease became known it took a lot of different forms of different names and the virus had been identified that we know today and later and you know at that time it was clear that women and children had been growing numbers of women and children had been identified as being infected as well. And my family situation of change was moving down to Washington area. And I wanted to be able to see if the

needs that had been identified and the services that had been provided would be applicable in a different population. I had interviewed of the NIH and the chief of pediatric oncology branch at that time had a goal of incorporating pediatric HIV into his existing pediatric oncology program and wanted somebody who has started programs who had a clinical background as well as a research background and that was the beginning of 1985.

[00:05:31] One of the things that I'm very familiar with having served on board of directors of an AIDS organization is historically as you mentioned the virus has predominated and that the gay community and the research has shown that a lot of organizations have difficulty changing their focus from providing services to say gay white men to other individuals who are now disproportionately impacted by HIV. As a woman can you tell our listeners what the process was like for you in the 80s when you as a woman were moving into this area that seemed to be impacting so much of the gay community as opposed to communities of color and women for example. It was it was a challenge to be able to first work in an area that was pretty enigmatic and people weren't clear of what was happening. The nature of this illness. Who was going to be impacted by it whether it was quote unquote contagious and it's something that really pure it to be fatal. I mean most of the young men that I've worked with in the very beginning died within two years of the time that they first presented in the hospital. And so you're working with something with the stigma you're working with something that's fatal you're working with something that is unknown and those three areas can cause significant stress for for a professional as well as for the population that you're working with. I think one of the areas that when you are not part of the community that's greatly impacted is you can have a little bit more distance in some ways.

[00:07:20] And what I mean by that is that for many of the young gay men professionals who are trying to be able to serve their community and serve them beautifully they too are so concerned to looking themselves to having have spots today they were losing people by the day. So you're grieving at the same time you're trying to be able to provide services and you are concerned about your own well-being being a woman not knowing that women are also risking their time again. Give a little bit about the distance and objectivity to see what was going on and to be able to intervene to help the staff as well as the Quantico patients who are coming in. And so I think that that was actually there was a gift so that I was able to move a little bit quicker. I think that having somebody who is not frightened for themselves at the same time and has to be able to just give 100 percent to that community was also something that probably made it easy to be accepted. I'm having a clinical background being very familiar with the community already you know having a predominant part of my my private practice at the time is also was also a client and so that part was not a transition for me it was dealing with an administration and it was dealing with other people who really weren't ready to embrace this new disease and the resources that it would take more importantly.

[00:08:47] And for any professional whether it is HIV or a different disease or something that's going to come up in the future is not getting caught up on the title of the disease but who the people are and getting to be able to know them and how they perceive what's going on in their own lives and what they need and what their concerns and fears and worries are and what they want in terms of services to help them to be able to adapt to adjust to and to be able to move forward. And so having a research background to be able to go in and ask them what services do you need. And over time those services change as well. I was able to develop a program that reflected the needs of the population. At that time and by continuing to do needs assessments ongoingly we were able to develop services that were based on the needs of their population as that population and the disease was changing. And now as the disease continues to change that is impacting more communities of color and people of varying ages. I know that much of your research has focused currently on children self disclosure other HIV status to peers to others. Can you help our listeners to understand how they as helping professionals could prepare younger people living with HIV to self disclose

their status. You're talking about children self disclosing it actually have to step back a little bit. Really depends on how the disease was disclosed to them so many parents waited long periods of time before they were ready to be able to disclose the diagnosis to their child. Many children learned about the diagnosis from other people other than their parents. So one does not you know takes their lessons of how they learned and how secretive this is and that's very powerful in terms of what they think is a safe thing to be able to tell other people so if one comes from a home where you do not tell anyone we do not share this outside of the home.

[00:10:46] That person may be much less likely to feel comfortable to be able to share that with other people when there's family members of their own that still don't know that they are infected or their parent is infected or they lost a family member or a parent to this disease. Right. So there is little secret to the first part just to get to step back a little bit. When I started when I came down to work in a pediatric program into start up pediatric program he went right back to the lessons I learned working in New York City and that is to begin with a needs assessment. I didn't know what the needs of these families would be so we took a population of the new population of parents who had a child living with HIV and many of them were in fact the parents were infected themselves. When we compare them to the needs of families who have a child with cystic fibrosis families help a child with cancer to be able to see what their differences are because models have already been created for other chronic diseases and then ongoingly having needs assessment to see how their needs and their children's needs change. As the epidemic changes as developmentally children get older and as we know children's needs changes through the developmentally. So one of the first issues that came up was that of disclosure. First many of these parents didn't expect their children to live first. They were told they weren't going to live to the five and they were told they weren't going to live until they were 10. So having to disclose the diagnosis didn't really feel like a priority to them. Why should I burden them with this information when they may not live anyway.

[00:12:20] Why should I put another you know difficulty on them won't they become more depressed more frightened more possibly stigmatized if I tell them they have a disease such as you know this disease which people are so afraid of. Once the disease once there were better treatments available and these children were beginning to live longer. This became a very critical point that the children needed to be able to know what it was. They had because they had to go the hospital frequently to be able to get medication and were being asked to take medication many times a day and wanted to know why you know so clearly as they were becoming adolescents to be educated to be able to avoid these behaviors where the disease can be transmitted. So there were a lot of opinions at that time. The child should be told tell the child immediately you really have to tell your child or don't tell your child your child cannot deal with this right now. Your community will not accept this. In time you could tell your child but there were no studies that were done that looked at what are the factors associated with the parents decision to disclose the diagnosis to their child or not disclose that diagnosis to the child. What are the factors associated with the parents decision to disclose their own status HIV status to their child who's infected rather children who are not infected. So the first disclosure study that we had done was to be able to look at that and we had approximately 100 parent child pairs and we looked at factors associated with a decision to disclose or not disclose.

[00:13:57] And we learned what factors would be associated with a parent being ready to disclose why they had waited. We interviewed the children as well. Obviously not the children who didn't know that. How do you go about changing who knew and about when they were told who they were told by. What would they want to have been done differently if they felt they were being told that they were told at the right time and by the right person. So we learned a lot from that and we also learned about what happens when you don't disclose the diagnosis. And we also learned about what happened with timing the best timing to be able to disclose the diagnosis and also to be able to understand that this is just telling a child that they have HIV is one step. If you think that you're just

going OK I told them and I have to address this again. It really takes a long time to be a book to someone and having the words or the letters HIV intellectually understood is very different than the first time you have an infection and you're hospitalized because of this HIV or you disclose this to someone and that person may react favorably or not favorably. It then takes on a whole new meaning. So disclosure is a process that takes a lifetime because it's different with each person. So when a parent in a family is very open about the diagnosis they may be the child may be very open with other people in their lives.

[00:15:18] When it's been a secret not surprisingly it often is kept a secret for parents who believe that they're ready to start discussing with their children their children's HIV status are their particular ways that you have found that are helpful for parents to begin that process of discussing with their children the children's HIV status parents rarely feel that if they're ready. They feel like it's the right thing to do. And it's the important thing to do. But it's something that they don't want to have to be able to do. Imagine you have to tell your child when you have a disease that there is no cure for and that you will have for the rest of your life and that can be life threatening. Imagine then telling them that I transmitted this disease to you and to this other people that are in your life may also have been infected. And who these are the people in your life you know and other people who don't know and you know if I get sick from this disease you know who would be there to be able to take care of you which is one of the first questions a child asks. So the process of disclosure is one that is a process. Sometimes there's other secrets that you really need to be disclosed first such as it could be paternity issues that could be if other people in the family had been infected or previous experiences of family situations. Some of these children have already lost parents and you know and are now being adopted or in foster care but didn't know what their parents had died. So it's a process actually very individualized.

[00:17:00] But we do begin and it's critical that all mental health providers that are working and health care providers that are working with children living with HIV work with their family from a very young age to be able to have open communication with them about their illness. That doesn't mean they need to be able to start and tell them a false diagnosis disclosure about what they have and what this means it means having works to build on later on so that there is a sense of trust. So we work from the very first time that we meet a family on whether what their feelings are about disclosure and if they're not ready to begin to respect that. In fact one of the findings from the study is that 65 percent of the children but they were told at the right time and by the right person and we need to respect that the parents know these children better than they do. And when timing may be right we also learned that they were glad that they were heard about the diagnosis from their parents and the ones that were most upset about the disclosure are those who heard about it from a physician and be a parent couldn't even tell them themselves. So we learned a lot from this study about how and when to be able to disclose but to work with families from a very early age about the process is critical. So we may say what we're actually using now and they say we used the word. So I don't forget the virus and the viruses.

[00:18:27] We're going to take medicine to be able to kill the virus to stop the virus from hurting you and if you need to change medicine you can go back and say Do you remember what I told you you had a virus and we weren't needed to be able to take medicine those medicines weren't working anymore so we're going to need to take new medicines and they could add a little bit more about the virus. In time they could be able to say Do you remember when I told you you have a virus and we're taking medicine this is the name of the medicine you're taking the virus the name of the virus. And this is what they do. So it's going back to paving a road to they can always go back and travel and the child is not coming back to them later and say well what else haven't you told me. Each conversation is Do you remember when I told you. And they can build on that. Depending on how much the child may want to know depending on how much the parents are comfortable being able to share at that point in time really depending on what's going on with the child medically so that

they're not being put in a position to have new procedures being done which they don't understand what's happening. But the decision to disclose and how much to disclose is based on many factors one the child's cognitive abilities to it's the parents emotional well-being. If a parent is feeling this is all new to them and they're feeling very overwhelmed and feeling very guilty I'm so sorry I'm so sorry. This is not the time to be able to disclose if the child is going through a crisis. This is not a time to disclose.

[00:19:54] If the concern is the child is the type of child is going to tell everybody you know you want to be able to be prepared for that to have people in your life that the child can talk to. The worst thing America do is say you can't tell anyone because what's the person the child wants to do. It's got to leverage. So if you say if you want to talk to other people that come to me first and want to make decisions together. But these are the people that you can talk to. It's a very different message than you can't tell anyone. It's also based on other disclosures. If there are other disclosures to me made those really should happen first. But the most most most important part is the open communication and a sense of trust between the parent and the child. Because there are going to be other difficult situations down the road. And you want to be able to know that the child can come back to be able to talk to you about those and you can be able to go back and talk to you about any other changes because HIV the thinking of it has shifted from being a terminal condition to being a chronic one. And I know many people when they think HIV we get the catastrophizing and they think oh my goodness that means I'm going to die soon. And even though we know that that is not necessarily the case how can we help parents and how can parents help their children who start disclosing their HIV status if they begin to hear from others. Oh my goodness. This means you're going to die.

[00:21:20] How can we provide help to the parents that the parents can help their children to realize that's not necessarily the case for them. Every family struggles with this. When there's anyone in the family who has any kind of chronic or even life threatening disease but for HIV that's magnified because early especially early in the epidemic there have been so many losses so many of these children have lost friends that they've met in clinic and spend time with that are no longer here. Many of the children in fact the most recent study it was about 50 percent of the children who have survived have lost a mother and about 48 percent lost a father to the disease. So when the message now is that you can live. That's a loaded message one because it's true. If they take their medicine at this point in time in the epidemic the virus can be to control. And it is seen more as a chronic illness. But two, there's often survivor guilt. Why am I living when other people are not. Why am I still here. My own mother and her father died of this disease. OK. How long am I going to be OK. If there's still is no cure to this disease. Am I going to get the same symptoms that my mother or father had and maybe who's going to be there for me. So while this is now considered to be and should be a chronic disease in many of these children's immune system bounded and they could be able to make plans for the immediate future of their life. And most are doing that there's still a tremendous amount of uncertainty. So to just tell somebody that you're living and you're doing well.

[00:23:16] And your viral load is unpredictable and go ahead and go make plans without allowing them to be able to think about the possibility that one day they too can get sick and they still are grieving the losses. It's a mistake if you want to help them to be able to move forward. So it has to be there at the time to be able to acknowledge that it is still an uncertainty of what's going to happen in time. And if you did get really sick what would you want. Who would you want to take care of you. Would you to be one of the things that are most important to you. How would you want to be remembered and to be able to take that and address that head on. So then they can take that energy and be able to move towards something. But if they're constantly going back to the what ifs want to be able to plan for the future. So we do we address that and we in fact we have a study right now looking at creating advanced planning guide for adolescents and young adults living with a life limiting a potentially life threatening illness and it's open to children adolescents and young adults

living with cancer and HIV infection. Well Dr. Wiener thank you very very much for joining us. You've been listening to Dr. Lori Wiener discuss her work with children with HIV AIDS and their families to hear more about her work with children with HIV AIDS. Over the last three decades check out the distinguished scholar series of the Buffalo Center for Social Research at our website. Thanks for listening.

[00:24:52] And tune in again next time for more lectures and conversations on social work practice and research. Hi I'm Nancy Smith 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 through our programs and what we do. We invite you to visit our Web site at www.socialwork.buffalo.edu Here at UB we are living proof that social work makes a difference in people's lives.