

Episode 119 - Dr. Dona Reese: "A Friendly Face:" Addressing Barriers to Hospice Care for African American Clients by Hiring African American Social Workers

[00:00:08] Welcome to in social work. 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 social work is to engage practitioners and researchers and lifelong learning and to promote research to practice and practice to research. We're so sure hello. I'm Charles Syms one of your host of in social work. I'd like to take a moment to address you our listeners. Thanks for downloading more than 400000 of our podcast. We'd like to know what you think of them. Please take a couple of minutes to tell us what you like or don't like about the podcast. If you're an educator and you're using our podcast and your courses how are you using them in your teaching. If you are a professional practitioner how have the podcast influenced your work. We would also like to know what you'd like to see us do next. Please go to our website at www.insocialwork.org and click the contact us tab. We look forward to hearing from you again. Thanks for listening care. Comfort compassion dignity. These are words often used in descriptions of hospice. The National Hospice and Palliative Care Organization reported that in 2011 over a million and a half people utilized hospice services in the United States. The report found that at least eight out of 10 people utilizing these services were white. However only about eight and a half percent were African-American.

[00:02:01] Further a study highlighted by today's guests found that just 2 percent of the hospice staff and 1 percent of hospice volunteers were African-American. Dr. Dona Reese is a former Hospice social worker who has conducted research on hospice since 1994. Dr. Reese is an associate professor of social work at Southern Illinois University School of Social Work. Her professional practice also includes work in child welfare and residential treatment for children domestic violence emergency room social work and private mental health practice. However it was her work in hospice that inspired her to earn a doctorate and move to researching the variables that influence Hospice social work outcomes. This work has included the development of the social work assessment tool. Dr. Reese has previously been a member of the social work faculty at the University of Illinois at Urbana Champagne the University of North Dakota and the University of Arkansas at Fayetteville where she also served as a faculty member in the interdisciplinary Public Policy Ph.D. program. She has authored a number of journal articles and book chapters on the subject of hospice and professional social work practice in hospice. Dr. Reese has served as the leader of the social work section of the National Hospice and Palliative Care Organization and Health Disparities scholar at the National Institutes of Health. She was the founder of the spirituality symposium at the Council of Social Work Education and was a member of the first board of directors of the society of spirituality and social work. In this podcast Dr. Reese will discuss variables that seem to influence African-American hospice use.

[00:04:04] She also talks about her work to increase the number of African-American MSW students in hospice placement and offers her thoughts on what must be done to increase the number of African-American social work professionals working in the hospice environment. Dr. Reese believes that this can be another step towards increasing the use of hospice services by African-Americans. Our guest was interviewed by Dr. Adjoa Robinson assistant professor at the School of Social Work. This is Adjoa Robinson assistant professor at the University at Buffalo School Social Work and my guest today is Dr. Dona Riese associate professor at the School of Social Work at Southern Illinois University. Thanks for joining us today Dr.Reese. My pleasure. We'll be talking about today is your word holos a friendly face addressing barriers to hospice care for African-American clients by hiring African-American social workers. I wonder before we start talking about

your latest research a little bit about what you think is unique about Hospice social work school social or medical. Those were your words. As a hospice social for several years and you've recently written a book about Hospice social. That's right. Well what's unique about it. Well of course the field of medical social work in general is becoming more and more important as the Baby Boomer generation ages because as they get older we're more likely to need medical care. And so that's becoming an important field. And then Hospice social worker it's a specific area within medical social work that is unique because it's working purposely with people who are terminally ill and helping them adjust and helping their families adjust and helping.

[00:06:09] The experience of dying to be a positive one which sounds crazy if you haven't thought about it but it can actually be an inspiring experience which actually is what inspired me to go back to school and do research in this area because I was so amazed by my experience as a Hospice social worker just observing what people experience at this time of their life. And I gather that in your experience you had seen a lot of African-American clients utilizing hospice. So your research went in that direction into investigating why that might be. Exactly. I was inspired by my work as a social worker in hospice to go back and get my Ph.D. to do research in this area. And as I was doing my dissertation the first thing I noticed was that the African-American patients that they had there in hospice were young and had AIDS. And this was back in the early 90s late 80s when AIDS was a terminal illness more so than today because now we have better treatment. But the patients they had there were very different from the general African-American population. So I started out there to try to find out why. You recently conducted a national study. Can you tell us a little bit about that you discovered some reasons why. Yes actually I've done a lot of different studies trying to find out why there were so few African-American patients in hospice. And I found out about a lot of barriers for reasons why they're not there in hospice. And one of the barriers was the lack of African-American staff and because the staff in hospice was almost entirely white there. I did a national study that found that only 2 percent of the staff was African-American and only 1 percent of the volunteers in 207 hospices that I study nationally.

[00:08:14] And so this study will be talking about today was exploring reasons why American social work students do not want to work in hospice. So because a lot of the barriers to having African-American staff is lack of applications. So that was the focus of this study was to ask them what they consider working in hospice and why and why not. So tell us a little bit more about that study. What did you do and what did you ask how did you do it. What did you find out. OK. Well in this study we interviewed 10 female African-American MSW students and we conducted some qualitative interviews. We just asked them open ended questions about why they think there are so few African-American patients in hospice and would they work in hospice or not and some as well. I could tell you the major themes and the sub things that we found reasons for the overall lack of diversity in hospice. One major theme was hospice philosophy reflects the dominant Caucasian cultural values. And these differ from traditional African American cultural values and beliefs. Including the hospice philosophy acceptance of terminology. There is a traditional African-American culture. There's a preference to pray for a miracle. There is a belief that God will save the patient. And so to say yes I accept that I'm dying. I know that I'm dying could be seen very often as a lack of faith. So there was a difference there between traditional African-American views and the hospice philosophy. And then there's another barrier based on a history of mistreatment by the White healthcare system in America. There is a fear that the White hospice staff would not be providing all the curative care that's available.

[00:10:27] So African-Americans because of the fear of the white health care system and is literally is white they would prefer curative care over letting these white people say to them here sign this. Do not resuscitate order and accept that you're dying because of a history of mistreatment. There's a fear there. So that would be a reason for lack of diversity in hospice in terms of patients. I want to comment on both those things you just said first about the distress. There have been lots of research

that sort of validates that the distrust of the medical system Institute on medicine given to patients with the same profile the African-American would probably not get the treatment that they should versus the White patients. So there's a lot of work that the Berkel community has to do to reestablish trust. And I'm not quite sure how to say that. But to reestablish some credibility they'll treat it. When we were talking about the difference in values between praying for a miracle and accepting death I can't see how that would be very well to people off. Sure. You're at the end of your life when the core things that really matter to you are there in stark relief and to say that I'm just going to let go when it's not how you believe your whole life. I just see how that would be a real crisis or struggle for an African-American client who subscribe to that belief system. Yes. And I think the hospice's can respond to that in a culturally competent way and just be open to the idea that a miracle may occur.

[00:12:20] And the idea that it's now in God's hands which is really consistent with traditional African-American belief. There's great diversity among African-Americans. But the traditional call Christian belief would be thank god for performing this miracle in our patient's life and our loved ones life and they would think that it was in God's hands not in the doctor's hands to begin with. And so I think the hospice staff can respect that and say Yes miracles do occur which they do. People recover when they're not expected to recover and just say that it's in God's hands. And meanwhile focus on good quality of life and offering support to the patient and family and also the fact that God might be calling them home. The notion of homecoming is part of the African-American tradition. If you go to a funeral you hear the future say God called him from everybody except except that they celebrate that. That's right. It's a celebration. We love you but God loves you more. Absolutely right. And I've seen a case study of a African-American family that was saying thank God for performing a miracle for our loved one that then was able to change that to God we don't understand your will that be your will to take Mr. Francis that we pray you take her quickly and without pain that that perspective can change and it's focused on God's will. OK. So you were going through the different barriers so we talked to those barriers. Yeah that was the reason for the overall lack of diversity in hospice. Those are the major themes in this study with these MSW students and the next part of that is the reasons for the lack of an African-American staff in hospice.

[00:14:15] One was just a lack of interest in the field and that you'd find that with anybody that may not be their interest but the rest of the reasons given may be seen as related to African-American cultural and religious beliefs. Based on my previous research first this discomfort regarding the topic of dying. Now I know everybody has that as well but I've seen some civic taboos within African-American culture and discussing death and dying and also lack of knowledge about the field that may be particularly the case in the African-American community because of the lack of outreach by hospices. And then another one a participant thought that hospice is not oriented toward employing African-Americans. So that could mean that there is no deliberate effort being made to recruit African-American staff and it could also imply racism on the part of Hospice's. The final reason that African-American social workers are not interested in working in hospice is the lack of African-American patients in hospice. And we had participants saying I want to work with my own people. So part of their reason for becoming a social worker maybe they want to work with their own people and help their own people so that it's a circular problem. There's no African-American patients in hospice because there's no African-American staff but the staff do not want to work there because there are no African-American patients in hospice. And so the next part of the data was we asked why are there a lack of African-American patients in hospice. And they said the lack of African-American workers leads to the lack of African-American patients. So again it's a circular problem. So what's the solution.

[00:16:09] Well we have got some ideas and there are some things that we've tried. Now one thing I think this study points out is the importance of addressing hospice and social work education so that MSW students know about hospice and know about this as a possible career path. Secondly it

seems that community outreach by hospices is going to be the key solution to this that if you have to recruit patients and staff at the same time then you can do it by connecting with the community. And I think it's very helpful if the university gets involved like the local school of social work. And so that is what we did here in this community. We implemented a university community hospice partnership in a participatory action research project. And so we had one hospice involved and then we connected with diverse community leaders African-American community leaders several of their pastors in local churches because the pastors are the leaders of the traditional African-American community. And then we also had some leading professionals in the community on our team. So we developed a team and met and planned this project and it included a field placement. We placed some these students in this hospice and we wanted it to be multicultural so we didn't restricted the only African-American students because we didn't know whether they would feel comfortable they would be like the only African-Americans there and they were just students so we had some white students as well we were open to any cultural group that we definitely wanted some African-Americans.

[00:18:00] And then when they were there they provided a cultural competence training to the staff community outreach and public education sessions direct service to clients there in the hospice including a couple African-American clients that they had. And that gave the hospice the opportunity to hire them after graduation. Unfortunately we're very disappointed that none of these students were hired. After graduation the hospice said they didn't have any openings. Now I think that was a mistake if I was the director I would have created some positions there. So that didn't happen in this project. I think that that's a way to definitely recruits them African-American staff. But we found some success with this project in terms of we did see that six new African-American hospice volunteers signed up to New African American patients and we know that's only two. But we were told by one of the pastors on our team that they definitely signed up for hospice as a result of this project and we also saw significant differences in that people after our public information session while we did a pre-test before our presentation and after and we found that knowledge and attitudes about hospice were significantly different from pretest to post-test with the local people in the community. And then we also saw significant differences in cultural competence scores of the staff in the hospice that we did. Signs of success. And then I wanted to know that in a national survey that I did have hospice directors they also had a couple more very valuable recommendations. They suggested that hospices provide support for minority staff in seeking higher degrees and possibly if they got a scholarship they would have an obligation to work in the hospice after graduation. And then another suggestion hospices could provide outreach to professional schools to recruit minority health care staff.

[00:20:10] Those both sound like excellent suggestions. I thought so too. So I think that if we really make a deliberate effort that we can change the situation I think it's very important to change because I did find in another study that I interviewed caregivers of terminally ill patients who had had cause hospice care and compared their responses to a group of caregivers of African-American patients who had not had hospice care. One group had hospice care. One group did not. And I saw that the African-American patients and caregivers in hospice were far more satisfied than the ones that did not have hospice. I think it's very important to keep trying to address the barriers that we're finding to care for African-Americans. Did you find any regional differences when you did any of their national studies in terms of the number of volunteers or staff or even African-American users or. You know now that's a very interesting research question. I was not able to access that kind of data. And I think that would be very interesting and we can provide that information and if there are regions that are particularly having a problem then they could be aware of that. That's good. I would think so in areas that had higher concentrations of African-American people that there might be a difference there but perhaps there is a very interesting sign and also people that are very successful in working with African-American people I would like to know their secrets what they're doing right where there's a church in Buffalo you might want to contact. There's a hospice associated with

one of the African-American churches. So I imagine that could give you some good information.

[00:22:11] I don't know for certain but I think it is nonetheless under utilized. I don't know what kind of outreach has gone with other churches beyond the one that is officially affiliated with hospice but so those are some very interesting research questions and it brings something else to mind that NIH has pointed out that there's some evidence that if you compare white patients in hospice to African-American patients in hospice that the African-American patients are less satisfied with the care they receive in hospice. Now I haven't found that in my research because they've been very pleased when they get hospice services. But some studies have found that. And I am thinking that the reason for that may still be the lack of African-American staff because there's just a tendency that Galambos points out that if you're from a different culture you may just naturally develop policies and ways of practice that reflect your own cultural perspective and you're not as sensitive to a different cultural perspective. So it's very important to have diverse staff Yes and there's been a lot of research. Sure. It seems to be trending. There is university community partnerships are developing for targeting different issues just for that purpose because to bring in the perspective of the cultural comfort of peace into designing interventions so that they will be accessible acceptable and culturally relevant. And it's very empowering to courts to involve the community as partners. So that's the whole idea of participatory action research. We're developing a partnership and having equal input from the people who know what the problem is and how to address it. Now is that partnership still ongoing with your university and whether the hospice locations in Illinois.

[00:24:20] No. That was a research study that and that has now ended. That's a good question to go back and check whether any continuing effects are still in existence. There certainly is usage and there's fewer African-Americans deaths and less interest among African-American social workers but those in general in terms of the interest among social workers to live in work in hospice. I haven't conducted research on that but I'm assuming that's some of the same barriers would exist that maybe they're not familiar with hospice or they're uncomfortable with the idea of the topic of death and dying that I think that some of the reasons that the African-American students gave for not wanting to work in hospice are specifically more likely for them because of their cultural perspective. So what do you think policymakers should do research or should do and social work educators should do as far as policy. The Centers for Medicare and Medicaid Services which is the Medicare organization just passed a requirement that hospices show that they have made attempts toward cultural competence. Now that is groundbreaking that has never happened before that there was such a requirement. However I consider that very very weak and inadequate to just require them to show that they've made an attempt to get cultural competence I would think that they should be required to demonstrate cultural competence and they should be required to demonstrate outreach efforts one survey directors nationally. And they said that they didn't have funding for community outreach to me. I presented this to an audience at the National Hospice and Palliative Care Organization conference Lanier and somebody raised their hand and they said lack of funding or lack of budgeting.

[00:26:32] And I thought that was the key point that there is a lack of budgeting. And so I think that they probably need to be required to do that because we tend to have a for profit healthcare system I guess I could go on and on about that. Well and of course many hospices are not at all for profit and they provide free care to those who don't have health insurance. I'm not blaming hospice you know for being really bad in this area but still they're budgeting things to be focused more on billable services. Send somebody out and they can then build for that service. And rather than looking at the quality of care provided in a more broader sense and the well-being of their community I think probably they need to be required to do community outreach and demonstrate cultural competence not just demonstrate attend a cultural competence. It seems that there really needs to be someone inside the organization with a little sway that understands the importance of this issue and believes

that it's good all around good for folks in need of care as well as hospice organizations to put effort to put budgeting in this direction and perhaps this new mandate will spur them on a bit. But again it goes back to what you were finding that was not enough staff. That is you need more people in the pipeline to rise through the ranks to reflect that value and bring that issue to the table.

[00:28:12] Yeah and one key point that I found in terms of connecting with the African-American community is to quit their pastors on your board of directors and then you've got people at the top that will influence that process just like you're talking about. Probably somebody that understands. I understand. I guess for my own personal experience but to have a true in-depth understanding you need to partner with African-Americans so you need them on your staff and you need them on your board of directors. So what should researchers do based on what you what should happen next or what are you going to do next. My next step that I'm going to be involved in is further testing the social work assessment tool that measures social work outcomes. Number years ago the social worker section of the National Hospice and Palliative Care Organization. I was the section leader at that time we developed a social work outcomes measure called the Social Work assessment tool and that was the first and still is the only measure of social work outcomes in hospice that is based on social work research about what issues social workers should be addressing and are addressing and hospice and what outcomes we should be focusing on for clients. And so we developed and tested that tool and we're going to be looking during a new study now to look at how widely this tool is being used nationally and what people's experience is with that. How is benefiting them. There's ways that they think it should be changed in any way. So we'll be doing some further investigation about the use of that tool and possibly advocating for it to be an official part of the Center on Medicaid and Medicare services. The tools that they require to be used in hospice to evaluate outcomes very good. What are your suggestions for educators.

[00:30:23] We started off talking about your research with students and their need for for America's tutors to become interested in this area of medical social or hospice hospices. How can we as educators facilitate that. OK. Well there has been an effort now for a number of years among social work educators to advocate for the importance of including material on end of life care in social work education. When I first became a hospice social worker in the late 80s I had not been trained at all to do the job. And so that's one reason I went back to school to study it so I could try to contribute to the field and develop some educational content that at this point there's a lot of high quality educational content that we still have to advocate for schools of social work to include that and make sure that that's part of what they provide for their students because their students will be faced with these issues with their clients with death and dying and they need to be prepared to address them. And then of course there will be more and more need for hospice social workers as we find that every year there are more hospices in the nation. The number of hospices has gone up to about 4000 in America. And that's far more than when I was a hospice social worker. So there's more and more of a need for this and specifically it would address the problem we are talking about today. If we look at African-American social work students know about this problem and the specific need for hospice social workers then it would help to address that problem of the lack of African-American staff and hospice.

[00:32:18] So it is kind of still a new field and we still have to advocate for inclusion of this content in social work education. So we talked about many things in the last words the things we haven't touched upon that you'd like to address in just a couple of thoughts about that term in the title friendly face in one study I did. I asked African-American pastors why there are very few African-American patients in hospice. And one reason shared was the concern that African-American patients have a friendly face to comfort them and share and understanding of cultural differences and fears. So that's how I came up with the idea. The term friendly face I guess one question that arises is can you show a hiring preference for African-American staff. Is that reverse discrimination of course. I personally do agree with affirmative action principles. But going beyond that if you

were going to hire the most qualified staff member and you had a choice between highly qualified African-American professional and a highly qualified white professional one qualification that you're looking at would be an understanding of the cultural differences and fears. And so the person who would understand that most deeply would be the African-American professional I guess that would be my response to that question that might arise. How can we discriminate and focus more more on hiring African-American staff. I would say hire the most highly qualified and you would find very often that a African-American person was most highly qualified especially for the community outreach and direct service to African-American clients Kleinhenz well that's great.

[00:34:20] Well Dr. Reese thank you so much for taking the time out today to talk to us about your research on the African-American students and their interest in hospice as well as African-American staff and hospice and how things need to change on that front. Thank you for inviting me. And it's a pleasure. You have been listening to Dr. Dona Reese discussing her work to increase the number of African-American MSW students and professionals in the hospice setting and its potential for positive impact on the use of hospice by African-Americans. Thank you for listening. This is Charles Syms your host inviting you to join us again for in social work Hi I'm Nancy Smyth professor and dean of the University at Buffalo School of Social Work. Thanks for listening to our podcast. We look forward to your continued support of the series. For more information about who we are as a school our history our programs and what we do we invite you to visit our website at www.socialwork.buffalo.edu.